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ABSTRACT

This serial issue features articles on the theme of empowering people with disabilities. First, there is a message from the Department of Education's Office of Special Education and Rehabilitative Services' Assistant Secretary, Robert R. Davila. Next, "Empowerment: Dependence versus Independence," by Frank G. Bowe, stresses the need for people with disabilities to incorporate empowerment and choices into their thinking. "The Road to Personal Freedom," by Carole Royal, describes a model self-determination program of the Protection and Advocacy System of New Mexico. "We Can! Empowerment of People Who Are Deaf," by Patti Singleton, examines principles of empowerment arising from the 1988 protest at Gallaudet University (District of Columbia). "Empowerment through Sports," by Doug Single, describes various integrated programs developed by Special Olympics. "Project EMPOWER: Self Determination for Young Adults with Disabilities," bv Jack Campbell, describes a program that uses experiential education activities and role modeling by adults with disabilities to help youths make the transition to adult life. "Empowerment through Peer Counseling," by Dale S. Brown, offers techniques in peer counseling and examples of its use with young people with learning disabilities. "Improving the Quality of Community Living To Empower People with Mental Retardation," by Charles Lakin, describes activity areas of the Research and Training Center for Residential Services and Community Living at the University of Minnesota. A special feature article is "Empowering Teachers To Help Students with Language Disorders in the Mainstream" (Judith M. Zorfass and Blanche Korngold). This article reports on a study which used a constructivist inservice approach to produce changed teaching practices in 10 teachers of grades 1-3, thereby facilitating language learning in children with language disorders. (DB)

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

# OSERS

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# Empowerment

UNITED STATES DEPARTMENT OF EDUCATION


Photo by David Snyder

# A Message from the Assistant Secretary

Robert R. Davila, Ph.D.

## The Empowerment of People with Disabilities

To me, and to many other people with disabilities, **empowerment** means enabling people to obtain the knowledge, skills, and abilities necessary to make their own decisions and to gain control of their own lives. Empowerment means leading independent, productive lives. We see empowerment at every level in the disability field today. We see parents empowering parents; parents empowering children. We see an empowerment movement growing within our communities; and we see individuals empowering themselves.

As parents, we must continue to look for ways to empower ourselves so that our children will be able to empower themselves as adults. Parents often ask, "What can I do as a parent to help my child get the most out of special education?" My answer is that, as parents, we can do a lot. One thing we can do is to learn and act on the rights to which our children are entitled under the Individuals with Disabilities Education Act (IDEA). IDEA provides parents and their children with disabilities with rights and guarantees designed for one purpose: to make sure that our children receive educational services based on their unique needs. As parents, we must assume a key role in all aspects of our children's growth and development both within the educational system and within the community. Empowerment must also be part of a larger goal to alter societal attitudes and to help the individual develop a positive self image, to develop confidence that can be used to further his or her prospects for the future.

Knowing and using the law, strengthening ties with others in our communities, learning and working together—that is empowerment at work. **AMERICA 2000**, the President's education reform initiative and its six national education goals, is part of a trend to return decision-making power to local communities and to state and local governments. Flexibility, the ability to make choices, and accountability to consumers are all part of this trend. Empowering local communities presents us with many opportunities for improving the services we deliver, but it also means that we have to be there, before the local school board, the state educational agency, and the state rehabilitation agency.

For those of us who are part of the rehabilitation service delivery system, it means that we have to rethink our strategies for advocacy and make sure that our voices are heard. We must lead the way toward community-based integrated services. We know that each person has something valuable to contribute to our society. Work within your local communities to address the needs and concerns of individuals with disabilities. Form partnerships with your community schools and with community organizations, collaborate on developing effective programs that benefit all individuals, not only individuals with disabilities.

As people with disabilities, we are living in a glorious period of our nation's history. Within the past two years, we have seen the reauthorization of the Individuals with Disabilities Education Act (IDEA), the landmark Americans with Disabilities Act (ADA) was enacted, and Congress has reauthorized the Rehabilitation Act. Federal funding for special education and rehabilitation services has increased substantially. Our problems do not result from a lack of legislative support or federal funding. Rather, these are problems that must be resolved by working within our own communities and looking within ourselves.

What is the federal government's role in the empowerment of individuals with disabilities? Empowerment has always been a guiding theme that directs our activities here in OSERS. When we talk about empowerment, we mean fulfilling one's potential and maximizing one's participation and productivity. Obviously, this will differ among individuals. There is no one standard to which a person with a disability must aspire.

Since becoming assistant secretary in 1989, I have introduced a number of initiatives to support and empower individuals with disabilities. I have sought to increase funding for research and training centers located throughout the country. I have sought to make our discretionary grant program peer review panels more representative by ensuring that more individuals with disabilities and from minority backgrounds serve as peer reviewers. We have increased the number of grant

*Continued on back cover*

# Empowerment

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A Message from the Assistant Secretary

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AN OSERS News In Print SPECIAL FEATURE

# EMPOWERMENT:

## *Dependence versus Independence*

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Photo by Jane Hoffer

Empowering Americans with disabilities to take charge of their own lives never has been more important—or more possible. Yet in many ways, it's never been more difficult.

The events of the past few years have led many to believe that the job already is done, at least in major part. They're wrong.

The fact is that, with respect to the bulk of the population of Americans with disabilities, we're standing still. The Americans with Disabilities Act (ADA) will help. How much it helps will depend not only on how it is implemented and enforced but also on how energetically Americans with disabilities adopt the lifestyles it makes possible. For millions, this means radically altering how they live their lives.

That's ironic in light of the efforts we've made to empower people with disabilities in this country. In this paper, I will raise the question: "What steps can we take now to empower the population?" I'll begin by outlining what we say we're doing, then track what we're actually doing. The evidence seems to suggest that we've empowered people with disabilities in legislation only; they've not yet incorporated into their thinking the life-altering choices new laws have given them. Until they do, they won't consider themselves to be empowered.

## Dependence versus Independence

The empowerment movement, broadly speaking, is that thrust in which we as a nation say to individuals with disabilities: "You can live a life of achievement, independence, and self-sufficiency. To assist you in that effort, we as a society will do our part. We'll enforce federal laws protecting you from unfair discrimination in education, employment, and everyday life. We'll also invest billions of dollars to provide you with the skills you need to support yourself in gainful employment. And we'll remove community barriers that stand in your way."

It's a beautiful sentiment, particularly to a civil rights activist like myself. I've spent twenty years helping to fashion this "independence message." I believe in it and I think most Americans with disabilities agree with me. The evidence, though, is that we still have much more to do for this message to take hold.

The counter movement, which I sometimes call the "dependence" alternative (Bowe, 1980), dates from the 1954 amendments to the Social Security Act creating Social Security Disability Insurance (SSDI) and the 1974 amendments creating Supplemental Security Income (SSI). These programs, together with Medicare (for SSDI recipients) and Medicaid (for SSI recipients), sent a very different message to Americans with disabilities. They say: "Society has an obligation to support you as people who should not be obligated to support yourselves. We're a compassionate nation. We won't expect you to work. Instead, we'll provide a safety net as long as you need one." Although this message has been modified by 1980 and 1986 amendments to the Social Security Act so as to remove some "work disincentives," the core message remains the same today. That's particularly true because many SSI recipients don't believe the Social Security Administration when it says that those changes make it safe for SSI recipients to work to support themselves.

*The first data from the 1990 Census of Population and Housing show that as few adults with disabilities were working to support themselves in the 1990 as was the case in 1980*

The evidence is that the "dependence" message has taken hold, and remains dominant, despite all efforts to wean dependent individuals with disabilities from it. The 1986 Louis Harris and Associates poll (ICD/Harris, 1986) found that two-thirds of adults with disabilities who were on entitlement rolls would rather be working. That's what they said. So one would expect that at least some would move from aid rolls to pay rolls.

It doesn't seem to be happening. The first data from the 1990 Census of Population and Housing show that as few adults with disabilities were working to support themselves in the 1990 as was the case in 1980 (Bowe, 1986a). The 1990 Census found that 60.6 percent of "working-age" (16-64 year-old) adults with work disabilities were not even participating in the workforce. These 7,782,459 adults neither worked nor were actively seeking employment when the Census was taken in April, 1990 (Bureau of the Census, 1992).

That only 39.3 percent of adults with work disabilities were in the labor force in 1990—after the 18-million-strong growth in jobs in the 1980s—is bad enough. That so few worked despite some $20 billion in federal, state, and local spending each year on special education, more than $2 billion in federal and state outlays on rehabilitation annually, and untold sums in private and public investments to remove architectural, transportation, housing, and communication barriers is, if anything, worse.

The recent numbers we have tell us that a majority of working-age adults with disabilities neither work nor actively seek employment. Today, putting it baldly, most adults with disabilities do not work. That's hardly the result we would expect from the concerted efforts we made to empower the population.

There's another concern. The costs of maintaining large numbers of Americans with disabilities on the entitlement rolls has mushroomed in recent years. Today, the SSA counts more than eight million persons with disabilities on its SSI and SSDI rolls. Entitlement programs such as SSI, SSDI, Medicaid, Medicare, and veterans benefits total more than $290 billion on the federal level alone. Whether we as a nation can continue to pay such costs is an open question.

Whether we should, given that these programs disempower millions of Americans with disabilities, is equally questionable. I have great difficulty believing that as many as eight million people with disabilities truly cannot work, given modern adaptive aids and accessible personal computers.

These programs are controversial among people with disabilities. Some argue that SSI and Medicaid are, in effect, welfare "handouts" that people can get just by being disabled, without having to work for them. Individuals with disabilities who worked hard to get an education, and then worked even harder to get and keep a good job, sometimes resent the fact that others with the same kinds of disabilities do not have to work to buy food and clothing, pay the rent, and receive medical care. Seen in this light, SSI and Medicare can rob people with disabilities of the incentives needed to become independent, self-supporting citizens.

Other advocates are angry because SSI and Medicare have many outdated rules that make it difficult to get off these aid rolls and onto payrolls. Some youth and adults with disabilities who benefit from SSI are still concerned they may lose eligibility if they engage in "substantial gainful activity," which usually means earning more than $500 a month. To place that figure in context, consider that it means making the minimum wage at a 35-hour-a-week job. A 1986 amendment—section 1619—to the Social Security Act allows some individuals to earn much more and yet keep Medicaid coverage. This program was designed to encourage SSI recipients to accept jobs paying more than the previously allowed amount. In fact, relatively few SSI recipients have left the Social Security rolls for payrolls under the section 1619 program.

These SSI and Medicaid rules disempower millions of Americans with disabilities. For some, SSI and Medicaid are necessary; these people, most of whom are severely disabled, have no real choice. Others can be helped, however. The foundation for empowering these people is largely in place.

## Empowerment Legislation

We mark the beginnings of the modern disability empowerment movement with the **Rehabilitation Act of 1973.** P.L. 93–112 required development of an "Individualized Written Rehabilitation Plan" (IWRP) by each rehabilitation client and his or her counselor. Two years later, in the **Education for All Handicapped Children Act of 1975**, Congress mandated the preparation for each child with a disability of an "Individualized Educational Program" (IEP). This document was to be prepared by school officials with the approval of the child's parents (and, where appropriate, of the child as well).

In addition, parents were granted remarkable rights to access all school records about their child, to appeal decisions with which they disagreed, and to materials in their native language. Later versions of the law, now called the Individuals with Disabilities Education Act (IDEA), added an Individualized Family Services Plan (IFSP) for infants, toddlers, and their families, and an Individualized Transition Plan (ITP) for adolescents age 16 or over.

Taken together, these written plans provide meaningful opportunities for people with disabilities and their families to take charge of their lives. Ideally, IEPs, ITPs, and IWRPs are developed in concert, permitting individuals with disabilities to map out a coordinated strategy for reaching personal goals.

Other legislation has reached deep into the private sector to empower individuals with disabilities seeking access to community life. The **Fair Housing Amendments Act of 1988** permits persons with disabilities to make access modifications in apartments and condominiums, forbidding landlords to bar such alterations. In addition, real estate agents, brokers, and landlords are required to practice nondiscrimination in all aspects of their work with prospective tenants and homeowners. The law further requires that all new apartment, cooperative, or condominium buildings with four or more units be constructed to be both accessible (wide doors, ramps, etc.) and adaptable (controls, cabinets, etc., that are readily lowered or raised).

The landmark **Americans with Disabilities Act of 1990** granted to individuals with disabilities the most far-reaching civil rights accorded persons with disabilities by any nation in the world. Reaching deep into the private sector, the ADA requires virtually every employer with 15 or more workers to practice nondiscrimination in employment and to make reasonable accommodations as needed so that individuals with disabilities may perform jobs for which they are qualified. It ended 20 years of acerbic national debate about access to transportation by mandating access to mass transit, commuter rail, and intercity buses.

The Act requires millions of businesses serving the public, such as stores, doctor's offices, entertainment centers, sporting complexes, and laundry establishments to make their services available on an "equal enjoyment" basis to customers with disabilities. The ADA also extended to persons using Text Telephones (also called TDDs) full and equal access to the nation's public switched telephone network, including all telephones connected to any of the country's 1,600 local exchange companies (LECs) and all of its long-distance carriers.

In addition, the Act granted to individuals with disabilities the right to charge violations of their civil rights in private-sector employment, in state and local governments, in "places of public accommodation" such as shopping malls and movie theaters, and in telecommunications.

These laws provide a framework for empowering people with disabilities. For Capitol Hill, the greatest challenge now is to create a single, coherent national policy on disability. To date, the two streams of legislation have proceeded almost unaffected one by the other. The 1974 SSI law and its 1980 and 1986 amendments, on the one hand, established and perpetuated the "dependency message." A separate stream of laws beginning with the 1973 Rehabilitation Act and the 1975 education law, and continuing through the 1990 ADA, created and expanded the "independence message." The task for the U.S. Congress now is to articulate to the American population of people with disabilities a single message. That will take time. Meanwhile, there is much we can do.

## Vehicles of Empowerment

The Americans with Disabilities Act charged federal agencies, notably the Department of Justice, the Equal Employment Opportunity Commission, and the Department of Education, with providing technical assistance and information about the ADA. Notable among the efforts undertaken to carry out these mandates are a $1 million contract from EEOC to the Disability Rights and Education Defense Fund (DREDF) to train disabled activists on helping to implement the ADA. The Department of Education has funded a network of ten ADA technical assistance centers, as well as several materials development centers. The Department of Justice awarded grants for more than a dozen projects aimed at accelerating compliance by such covered entities as restaurants, hotels, and labor unions.

Still, in view of the census information, we need something more if we are to fully empower tens of millions of Americans with disabilities. I like the idea of looking to "independent living centers" (ILCs). The Rehabilitation Act, as amended in 1978, created what is now a 466-strong network of local centers for independent living. Most congressional districts have at least one such center. The centers are governed and staffed largely by individuals with disabilities. These advocates are active at the local level, especially in peer counseling. Their focus on the community and their tradition of peer support position them ideally as vehicles of empowerment. I would like to see them focus their energies on informing community residents of their rights.

An excellent local project for an ILC would be to encourage each area resident with a disability to speak up at each store, restaurant, hotel, and other covered entity he or she visits in the normal course of events. It may not take much more than a comment—"I'd like to shop here, and I could, if you'd do what the ADA calls for." Multiplied over millions of people saying this in tens of millions of businesses, such small steps would do more to stimulate implementation of the Act than almost anything I can think of.

The women's movement accelerated in the late 1960s and early 1970s because of exactly such actions. Millions of women became aware of entrenched paternalistic attitudes and made the small, individual decisions to assert themselves as equals. The women's movement asked each woman to act on her own, at home and at work. That was something virtually every woman in America could do. Centers for independent living can ask Americans with disabilities in the 1990s to take similar small, local steps. Importantly, such actions permit these individuals with disabilities to begin to take responsibility for their own lives. As they learn what the laws require, and ask that local companies do those things, they'll empower themselves. ♦

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# The Road to Personal Freedom

Photo by The Road Project

Carole Royal
Director

The Road Project

## Introduction

Students with exceptionalities have diverse needs and abilities. Yet, these students also have one thing in common: they can express their own viewpoints and they can make informed decisions about matters that affect their lives. All students with disabilities need to be taught to take charge of their own lives. (Thomas, 1982). Their education should be organized by the principles that promote self-determination. (Deci & Chandler, 1986).

Self-determination refers to: the attitudes and abilities that lead individuals to define goals for themselves, and their ability to take the initiative to achieve their goals (Ward, 1988). According to the literature, the traits underlying self-determination include self-actualization, assertiveness, creativity, pride, and self-advocacy (Ward, 1988; Funk, 1987; and McGill, 1987).

There is evidence that indicates self-determination is altered by events or contexts. Yet, the general context surrounding events, more than events themselves, determines the degree of impact on people's self-determination (Deci & Chandler, 1986). Therefore, cultural diversity and low socioeconomic influences are of crucial importance as we consider appropriate self-determination educational programming for exceptional students. Thus, the following issues need to be addressed: (1) Self-determination characteristics—identification of self-determination characteristics and outcomes in minority cultures. (2) Relevant goals and skills—construct a curriculum within cultural framework. (3) Strategies—generate strategies for use at home to help students with disabilities achieve self-determination.

The Protection and Advocacy Systems of New Mexico is developing a model program, *Self-Determination: The Road to Personal Freedom (The Road)*, in conjunction with examining emerging principles of self-determination for students with exceptionalities from diverse cultures and low socioeconomic areas. This three-year project, currently in its second year, is funded by the Office of Special Education and Rehabilitative Services. New Mexico is an ideal environment in which to examine these issues since it is one of the few states where ethnic/racial minorities actually constitute a near majority of the population.

## Goals of the Project

The major goals of the project are to:

- identify the skills and characteristics necessary for self-determination;
- develop and test a curriculum which is sensitive to learning differences and provides varied classroom experiences designed to foster self-determination skills;
- evaluate the effectiveness of the program in developing self-determination skills among youth who attend special education classes;
- adapt concepts of self-determination to minority cultural perspectives;
- develop and test a multifaceted training program to support the self-determination process in the home;
- involve adults with disabilities in the project as information resources, role models, and advocates.

## Self-Determination Characteristics

During the second year of *The Road Project*, a rating scale was devised to identify the importance of various self-determination characteristics for people with disabilities. This scale was administered to a broad population which included people from minority cultures. Preliminary results showed no significant differences between any of the cultural groups. Further identification of self-determination characteristics and outcomes in minority cultures will be addressed during the third year of the project.

## The Students

The second year of the self-determination project provided instructional activities to 30 students who received C and D level special education services and classes at Rio Grande and Los Lunas High Schools. These high schools were selected based on their service to low socioeconomic and minority populations. The qualifying exceptionalities for 24 students included learning disabilities, communication disabilities, and behavioral disorders. Six students with mental impairments at Los Lunas High School also qualified for services.

The Self-Determination Team presented the curriculum to a ninth grade class at Rio Grande High School and to two classes of students ages 14 to 21 at Los Lunas High School. Seventy-eight percent of the students were from minority cultures. The instructional sessions were conducted for 50 minutes, once each week for two semesters. Eighteen students completed the school year and the Self-Determination Project.

## Curriculum

In *The Road Curriculum*, cognitive and learning strategies are integrated with self-determination concepts by patterning the activities in a spiral design. This pattern contains at least eight activities to provide a utilization level for each concept introduced; four activities are language based and four activities are creative and not based on language. This approach evolved, during the second year of the project, to better meet the needs of students with exceptionalities who were also affected by cultural diversity and low socioeconomic influences. The S-D team observed student responses and behaviors that supported Kavale's (1988) findings, which revealed a complex interrelationship among the phenomena of learning disabilities, brain dysfunction, and culturally-low socioeconomics. He also noted that methods provided for students with learning disabilities appeared appropriate for meeting the educational needs of students who have culturally-low socioeconomic influences. The S-D Team's observations and documentation would suggest the interrelationship may extend to include the phenomena of other exceptionalities such as communication disorders and behavioral disorders.

One of the most common descriptors, for children affected by cultural diversity and low socioeconomic influences, is outer locus of control (OLOC) rather than inner locus of control (LOC) (Baldwin, Gear, & Lucito, 1978). Whereas, an internal orientation is linked to self-determination, most project students at both high schools demonstrated behaviors of short attention to task and the inability to complete tasks without direct supervision which are associated with OLOC. Therefore, *The Road Curriculum* presents activities and experiences that emphasize goal setting, problem-solving, and creativity which are conducive to fostering a more internal orientation in students. Such experiences, extended throughout the curriculum, were intended to prepare the students to meet long term goals including contributing to their Individualized Education Plan (IEP and/or their Individualized Educational Transition Plan (IETP).

*The Road Curriculum* focused on the IEP/IETP as an avenue to provide opportunities for students to communicate their goals in assertive ways and practice the skills essential to becoming self-determined individuals. While the school districts' current IEP/IETP's were obviously well constructed for professional use, work with the project participants revealed that the plans were far too complicated for their understanding and input. All project students, even with help, had great difficulty finding pertinent information given on the forms. Generally, the educational goals listed on the individual plans appeared too external and remote for students to make a realistic contribution. After attending IEP/IETP meetings, students expressed confusion, and an overall inability to participate in a meaningful way.

*The Road* S-D Team purports that IEP/IETPs need to be "Student Friendly" and promote self-determined functioning. A "Student Friendly" IEP/IETP was developed for the third year of the project to be used in conjunction with school districts' plans.

Leisure and community activities, as well as jobs, resources, and job related skills were used as "hooks" to motivate students while they examined the relationship between personality traits, learning needs, future job options, and job training. Additional emphasis was focused on exploring student strengths and building self-confidence. Students discovered the significance of good communication skills and the importance of knowing one's strengths during interviews given by the local McDonald's manager. Surprisingly, the students had difficulty answering the manager's question, "Why should I hire you?" The necessity for students to be able to identify and communicate their personal strengths became evident.

The spiral design of *The Road Curriculum* blends accommodations, communication, self-discovery, and self-advocacy as strands throughout the units since they require mastery of interrelated skills. Examples of activities and student successes include:

Several members of *The Road Board* and a number of employees from Protection and Advocacy, most of whom have physical disabilities, mentored the students and addressed the importance of establishing accommodations and maintaining dependable support systems. This experience was ranked a favorite by the students.

Jimmy, a student with LD and severe dyslexia, reported with enthusiasm that he had passed the New Mexico driving test. He had requested a reader for the written test. The examiner checked with the department manager and then agreed to read the test to Jimmy. Through *The Road Project*, Jimmy knew his rights and was able to advocate for himself.

One of the students with brain damage, Daniel, had responded in anger to his teacher when she addressed his poor behavior. Later, with coaching from the S-D Team, using *The Road* techniques, Daniel approached the teacher, accepted responsibility for his behavior, and negotiated an improved outcome. Beaming, and somewhat surprised, he reported, "It worked!"

Student responses to "What did you learn in this program?" included: "to accept people how they are," "how not to be shy," "how to stand up to other people," and "I can go to college and have somebody read for me."

## Evaluation

Pre- and post-tests were used as evaluation instruments. Preliminary findings are presented in Figure 1. Although, analysis of data was not yet completed, when project groups' scores were compared to parallel control groups' scores, a significant difference appeared to exist.

## Families/Guardians

Since support from families/guardians contributes to the self-determination skills of students, families were provided the opportunity to receive information and training. The Self-Determination Team met with the families/guardians at least once before the training sessions began. During those visits family members provided insight into how they viewed their sons' and daughters' abilities to become independent decision makers. A multifaceted training program sensitive to cultural perspectives was developed to support the self-determination process in the home.

## Barriers

Now concluding our second year of work, we have identified barriers that we have addressed or that need to be addressed in the future.

- ***Student enrollment, attrition, and attendance.*** Cumulatively, 45 students were enrolled in the classes where *The Road Project* was presented. Fifteen students attended the S-D project class once or twice, never returned, and therefore were not pre- or post-tested. The project lost six pre-tested students due to attrition. This barrier was a general school problem.
- ***Amount of time.*** The instructional sessions were conducted once each week. This schedule limited follow-up and immediate feedback to students. It also restricted the attitudes and feeling tones necessary for self-determination to cultivate. Therefore, the curriculum was expanded to be taught as a one semester class.
- ***Developmental process.*** Self-determination is a developmental process that begins in childhood and extends throughout adulthood (Ward, 1991). Understandably, high school students with disabilities have had a greater rate of failure than other students. As a result of failure, students are more likely to exhibit learned helplessness, lack of motivation, and delayed skills which impede all facets of the process of

self-determination. Such student behaviors were observed by the S-D team during many project sessions. The self-determination curricula and project needs to be expanded to present a continuum of skills, provide identifiable stages, and training for parents, teachers, and others.

- *Denial of disability*. Since most project students' disabilities are hidden, they often wrestled with problems associated with denial. When asked how they qualified for special education services, they responded with, "I'm dumb," or "I don't know." This stance was more prevalent in the first class at Los Lunas than in either of the other two project classes. The wider range in age and exceptionalities of this class may have contributed to the students' responses.
- *Parent involvement*. The project families were very congenial and hospitable during home visits or telephone calls. Yet many did not attend training sessions even though they had agreed to participate. Contrary to students with physical disabilities whose parents may tend to overprotect them, some parents of students in *The Road Project* may actually underprotect them. The S-D Team developed a multifaceted approach to parent training to make the information more easily accessible to parents. This effort was initiated the second year, and will be evaluated the third year of the project.
- *IEP/IETP Process*. The IEP/IETP forms and procedures are not "student friendly." Each student needs accommodations and skills to play a responsible role in the decision making process in the IEP/IETP operation.

## Conclusions

The preliminary findings in the identification of self-determination characteristics in minority cultures. Hispanic and American Pueblo Indian, showed no significant differences between any cultural groups. Perhaps, cultural differences exist, not in the characteristics themselves, but in the factors supporting self-determination and the behavioral outcomes that indicate self-determination. Further investigations will be conducted during the third year of the project.

Photo by The Road Project

*The Road Curriculum* was constructed specifically to be sensitive to learning differences, to provide varied classroom experiences, and to foster self-determination skills within a cultural context. Preliminary second year data, which evaluated the effectiveness of the program in developing self-determination skills, indicated significant student gains.

*The Road* parent training program was extended to parents of the project students. A multifaceted program was developed to help parents reinforce self-determination concepts at home.

Barriers point to the necessity for a philosophical change in the educational approach for students with disabilities. Special education often focuses on remediation and on individual deficits of students rather than on those accommodations and self-determination skills that would enable the students to experience success. The Road Project supports skills and training for parents, teachers, and others that will bring about a philosophical change encompassing self-determination. ♦

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# WE CAN!

## Empowerment of People Who Are Deaf...

*An Empowerment Agenda for the 1990s and Beyond*

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National Academy
Gallaudet University

Photo by Gallaudet University

> ***"DEAF PEOPLE CAN DO ANYTHING HEARING PERSONS CAN DO... EXCEPT HEAR!"***
> I. KING JORDAN, 1988

### Introduction

The DPN (Deaf President Now) protest, during the week of March 6-13, 1988, leading to the selection of a deaf president at Gallaudet University was an excellent example of empowerment in action. With the resignation in September 1987 of Dr. Jerry C. Lee, 6th president of Gallaudet University, the door was opened for the possibility of the appointment of a deaf president to head the world's only liberal arts university for people who are deaf. The Gallaudet Board of Trustees had an impressive list of qualified candidates who were deaf, and a strong message was sent via an enthusiastic campus rally to enlighten the community that "The time is NOW!" for a deaf president to lead Gallaudet.

Photo by Gallaudet University

In spite of intense lobbying efforts by students, parents, alumni, and many faculty and staff at Gallaudet, the dreams of a deaf president were shattered with the Board's appointment of a hearing individual as Gallaudet's 7th president. This appointment was not well received by the student body, who promptly orchestrated a takeover of the campus. The deaf community promptly entered the picture and joined this effort.

By standing firmly together and being totally committed to their cause, the students, faculty and staff, alumni, and their families, and thousands of hearing and deaf supporters around the world were able to achieve their goal of a deaf President for Gallaudet.

## Principles of Empowerment

The events of DPN week were symbolic of a deeper, more pervasive movement towards empowerment which had been gathering momentum for the last several decades. The seeds of this movement originate in the earlier Civil Rights movements of the 1960s, the women's movement of the 1970s, and the development of technology in the 1980s which opened up new vistas for communication and program access for individuals who are deaf. The empowerment movement has set the stage for full equality as we enter the decade of the 1990s, armed with the tools of the Americans with Disabilities Act (ADA), and a growing, educated community of people who are deaf who have taken control of their own lives and are demanding a full active role in making key decisions about issues that affect them.

How does one become empowered? For people who are deaf, the following principles must be considered:

- Encourage research on deaf history and the development of Deaf Studies programs to provide the deaf community a means of sharing their cultural identity with each other, their families, the community, and the world.
- Support pride in being deaf and encourage Deaf Awareness Day or Week activities.
- Recognize the deaf community as having a unique identity and a unique language—ASL.
- Teach respect for differences among individuals.
- Place qualified people who are deaf in important leadership roles in programs and organizations for deaf people.
- Maintain a majority of deaf and hard-of-hearing persons as representatives on decision-making boards for programs affecting deaf people.
- Enforce all provisions of the Americans with Disabilities Act (ADA) to provide deaf, deaf-blind, and hard-of-hearing people with full access to society.
- Provide opportunities for socialization with other children or adults who are deaf.
- Educate parents about deafness and sign language so they can provide full communication to their child from birth.
- Increase the numbers of qualified deaf and hard-of-hearing teachers, counselors, and administrators in educational programs as positive role models.
- Require certified educational interpreters in mainstreamed programs.
- Provide full access to educational programs and employment training opportunities.
- Provide a tax deduction for the purchase of assistive listening devices such as Text Telephones and Braille TDDs.
- Include placement in residential schools as an option for children who are deaf.
- Require individualized education programs (IEP) tailored to the child's individual needs after appropriate evaluations have been done by professionals trained in deafness.

## Where Are We Now?

It has been four years since the Deaf President Now protest at Gallaudet. The passage of the Americans with Disabilities Act (ADA) in 1990 has opened the door to many areas previously closed to people with disabilities. The ADA has created countless opportunities for people who are deaf to access benefits and services on a previously undreamed-of level. The ripple effect of the ADA has improved access to and communication with the hearing world via relay services and interpreters, and expectations have been raised that have resulted in a shattering of the glass ceiling that kept people who are deaf from advancing to higher level jobs.

Deaf children now dream of becoming doctors, lawyers, and presidents, with so many positive role models now visible for them to emulate. These are tangible signs that people who are deaf have become empowered and are making significant contributions to the world in which we live.

## Where Do We Go from Here?

Given the current rosy picture of people who are deaf in leadership roles, and the positive strides made in terms of access, it is too easy to rest on our laurels. There are still too many deaf people who do not have access to the education or technology that can improve the quality of their lives. Deaf high school graduates with a third or fourth grade reading level are more the norm than the exception. This is clearly unacceptable, especially in light of the demand for excellence and the National Goals advocated by the Secretary of Education in the AMERICA 2000 education reform movement (Rosen, 1992). The Commission on Education of the Deaf (COED) report to the President and the Congress stated quite clearly that *"the education of deaf children in this nation is unsatisfactory, unacceptably so"* (1988).

We want for our deaf children the right to learn, the opportunity to compete on an equal basis with hearing peers, the right to equal access to all programs, goods and services in the community, and the responsibility to make meaningful contributions to society. Our deaf children are our future, and we must invest in their education to equip them with the skills and knowledge to live productive, independent lives.

The Empowerment Agenda for the 1990s and beyond must include the following to provide excellence and equality for children who are deaf and hard of hearing:

- appropriate screening and assessment of each deaf child's unique visual and hearing capabilities and communication and language needs, and the continuation of screening services throughout the education experience;
- early educational intervention to provide for acquisition of a solid language base;
- parents with fully informed participation in the educational planning for their children;
- adult role models who are deaf or hard of hearing;
- placement in programs with age and language peers;
- qualified teachers, interpreters, and resource personnel who communicate effectively with the child in his or her best mode of communication;
- placement best suited to the child's individual educational needs and his or her social and emotional needs;
- individual considerations for free appropriate education across the full spectrum of educational programs;
- full support services provided by qualified professionals in their educational settings; and
- full access to all programs in the educational setting. (Rosen, 1992).

## What Does Empowerment Mean for People Who Are Deaf and Hard of Hearing?

Empowerment means that no deaf child will ever have to grow up without positive deaf role models. Empowerment means freedom to communicate in whatever method is most comfortable and understandable. Empower-


Photo by Gallaudet University

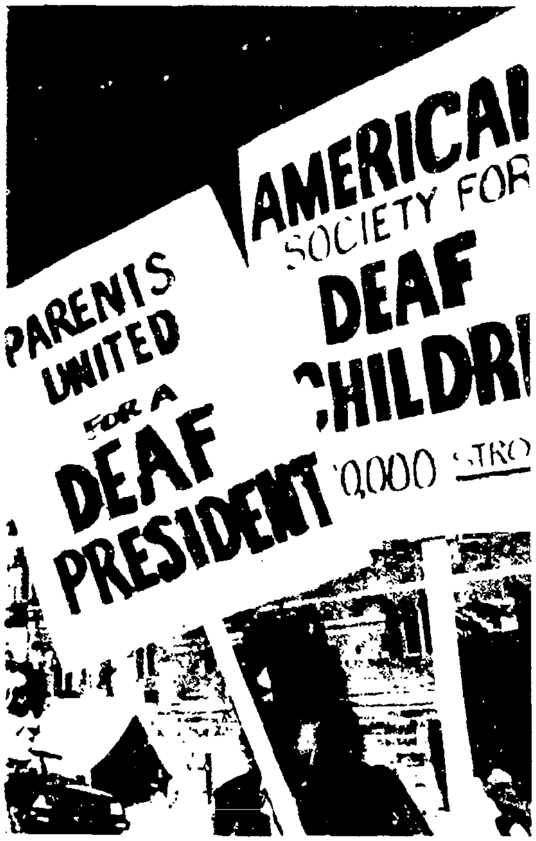

Photo by Gallaudet University

ment means recognizing individual differences and teaching a healthy respect for diversity. We can find strength in diversity if individual differences are respected. Empowerment means continuation of quality education throughout the lifespan and educating parents to become active partners in their child's education. Empowerment means freedom to develop, to grow, and to express opinions that are sometimes contradictory and painful when they differ from those of the hearing world.

## Conclusion

With so many doors now being opened to people who are deaf and hard of hearing, what is left? What new frontiers remain to be conquered and barriers overcome in the recognition of people who are deaf as equal first class citizens? With so many options now available to the deaf community, there will be even greater advances made as we begin to take advantage of these opportunities.

Unfortunately, the major remaining barriers to full access and acceptance by society cannot be legislated or mandated by Congress; these are the **attitudes** of nondisabled people toward people with disabilities. By educating nondisabled people about what people who are deaf and hard of hearing can do, given equal access to the same benefits enjoyed by others in society, and the positive contributions they can make to the community, these attitudes will change.

Hearing people are an important part of the deaf community. They are part of our families, friends, co-workers, and have important roles in the deaf community as interpreters, teachers, and advocates for equality and excellence in our programs. Partnerships between hearing people and people who are deaf can go a long way toward overcoming any attitudinal barriers. Deaf and hearing people must work together as visible, active partners in fulfilling the American Dream, and as Glenn Goldberg, a lawyer, said: *". . . through our united efforts, the door to full and equal citizenship is now finally open. Now together we must walk through and make sure it will never close again"* (Goldberg, 1978).

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# EMPOWERMENT through Sports

Doug Single

Special Olympics

Photo by Ken Regan/Camera 5

Whether participating on the field or cheering from the grandstand, athletics play a major role in people's lives by helping to build self-esteem and promote physical and mental health. Schools, park and recreation departments, community organizations and health and fitness clubs provide opportunities for people to participate in the sport of their choice. However, for most children and adults with mental retardation, opportunities to participate in athletics are often limited for two reasons. First, many do not receive the additional training and competition opportunities needed to develop sports skills and learn how to be good competitors; and second, sports programs geared to people with disabilities are often not offered by schools and other groups.

Participation in athletic activities is one of the strongest avenues for people with disabilities to achieve full potential and to co-exist as equals with nondisabled persons. Competition for athletes with disabilities is expanding at an incredible rate and has greatly influenced society's perception of people with disabilities. Sports training for athletes with disabilities is producing a corps of elite athletes, many of whom are capable of competition with their non-disabled peers in regular sport competitions without any adaption.

## The Letter and the Spirit of the Law

Although public and private educational agencies have long provided intramural and interscholastic sport opportunities for both boys and girls, the right of students with disabilities to benefit from the same opportunities has only recently been legislatively established. Since the passage of the Individuals with Disabilities Education Act (IDEA), formerly the Education of all Handicapped Children Act of 1975, and Section 504 of the Rehabilitation Act of 1973, all schools are required to provide sports opportunities for students with disabilities. Many schools have been confused over these mandates and their responsibility to provide sport opportunities. These laws further require that individuals with disabilities must have an equal opportunity to participate in and derive the same benefits from sports programs available to students without disabilities. Schools must now recognize their role in preparing students with disabilities to benefit from the many sports, competitive, and recreational opportunities available to them.

Practices that exclude persons with disabilities from participating on sports teams still abound. To exclude a person solely on the basis of disability may violate the Americans with Disability Act (ADA), Section 504, and due process. Each person with a disability should be individually evaluated to determine whether appropriate, nonthreatening sports participation is possible. Newly developed training, conditioning, and coaching/teaching techniques for athletes with disabilities require that teachers, coaches, and athletic trainers update their knowledge and skills to correspond to the times.

Academic restrictions requiring athletes to maintain a certain grade point average or grade equivalent average to compete in sports may unfairly exclude students with learning disabilities, emotional disturbances, or mental retardation who have the ability to excel on the athletic field. Some progressive schools base athletic eligibility on the Individualized Education Plan (IEP) progress.

## Sports and Inclusion

Most organizations for athletes with disabilities exclude nondisabled individuals from competing in sanctioned meets. Inclusion is a primary issue creating tension between the organized sports programs for athletes with disabilities and some school and adult service systems. Many believe that segregated athletic programs contradict the inclusion movement because only individuals with specific disabling conditions are eligible for the various sports programs. Since these sport organizations exclude people without disabilities, they are viewed as segregated programs by some individuals.

Recognizing the need to include athletes with and without mental retardation on the same team, Special Olympics developed three inclusive sports programs collectively called Unified Sports Activities. These three inclusive sports programs are: Sports Partnership, Partners Club, and Unified Sports. The programs are being embraced by school systems, sports clubs, and parks and recreation programs across the country.

## ANDY LEONARD— World-Class Powerlifter

Andy Leonard is a powerlifter. He is one of the top amateurs in the country. He ranks among the top five in the United States, not just in Special Olympics. What Andy has been able to accomplish would be remarkable enough even if you didn't take into account his difficult start in life. Born in Vietnam in 1969. Andy's parents were killed in an artillery attack when he was only three years old and he was taken to An Lac orphanage near Saigon. A raging fever at a young age left Andy with a form of mental retardation which, among other symptoms, made it very difficult for him to process thoughts into language. Andy also had nerve damage to the right side of his head and a badly infected ear drum which required surgery to rebuild.

The Leonards read about the children from An Lac and decided to adopt Andy. When he arrived in the United States, the small boy was so weak he couldn't manage to turn the pedals on a tricycle.

As a youngster. Andy grew stronger and became active in sports. In fact. on a YMCA team. Andy qualified for the state meet in breast stroke. In high school, however, he found that he could no longer keep up with the other students his age in sports. His special education teacher convinced Andy to get involved in Special Olympics and from that point on, there has been no stopping this truly gifted athlete. Clyde Doll became Andy's coach and confidant and, in 1990. coached Andy to a fifth place finish at the American Drug Free Powerlifting Association (ADFPA) National Championships. At the 1991 Lifetime Drug-Free National Competition, he finished second, just 14 pounds behind the first place lifter. Andy is also the current two-time ADFPA Pennsylvania state champion for his weight class.

One of Andy's most satisfying moments came during the 1991 International Summer Special Olympics Games in Minneapolis/St. Paul, Minnesota. Pressed hard in the finals by another outstanding powerlifter. Andy lifted a personal best of 402.2 pounds, nearly four times his body weight, to win the gold medal.

Clyde Doll says that it's not just the growth in Andy's strength and lifting ability that has made working with this young athlete so rewarding. "Andy has increased his self-confidence almost as much as he's increased his strength. Even his ability to speak has improved through his exposure to powerlifting and the media. He's come just such a long way."

Today Andy is a truly self-confident young man. He has his own apartment, car, and works full time. He is involved in Boy Scouts, working towards Life Scout, and is a member of the Order of the Arrow—an award presented by his peers in recognition of his service to his scout troop. Andy has an active social life and finds time for camping and other outdoor activities.

Andy continues to be devoted to Special Olympics and spends a great deal of his time helping other athletes with their powerlifting techniques. Small of body but big of heart, Andy Leonard exemplifies how sports empower people with mental retardation to lead rich, rewarding, independent lives.

Special Olympics sports programs enable individuals with mental retardation to develop physical skills, fitness, self-discipline, self-respect, comradship, and personal satisfaction through competitive and recreational experiences. These same skills are also needed to compete successfully in the world of work. The need to win and to be recognized for one's achievements is fundamental to everyone. Success in the sports arena provides an opportunity for persons with disabilities to attain acceptance, approval, and recognition.

## SARY SOSA—The Girl In A "Shell" Who Became A Cheerleader

When Sary Sosa was five, her family left a life of poverty in Puerto Rico and settled in Philadelphia. Twelve-year-old Sary entered Linda Carroll's special education class an invisible girl who lived in a shell. She didn't speak, she didn't look up. She had no friends, and

## Special Olympics Sports Partnerships

Special Olympics Sports Partnerships place athletes with mental retardation on existing sports teams for athletes without disabilities. All athletes train together but compete against athletes of comparable age and ability. These Partnerships offer individuals with mental retardation a variety of sports training and competition opportunities at very little cost. Training and competition are supervised either by the team's head coach in a particular sport or an assistant coach specifically assigned to coach the Special Olympics teams. Athletes without disabilities from existing sports teams serve as peer coaches, scrimmage teammates, and boosters during competition. In schools, athletes with mental retardation train and compete alongside the varsity, junior varsity, or club teams. They wear school uniforms, ride the same team bus to competitions, participate in, and are recognized in school sports awards ceremonies, qualify to earn school athletic letters, and represent their school in Special Olympics local, area, sectional, and state level competitions. In community sports programs, athletes with mental retardation train and compete alongside recreation league teams of comparable age. They wear the same team uniforms, travel with team members to competitions/meets, and represent their club in Special Olympics competitions.

## Special Olympics Partners Clubs

Special Olympics Partners Clubs are sanctioned school clubs formed to provide volunteer peer coaching to Special Olympics athletes. Club members also spend additional time with Special Olympics athletes enjoying other social and recreational activities in the school and community. Partners Clubs help nondisabled students and Special Olympics athletes appreciate the value and strengths of each other as individuals. A bond of friendship and respect is developed, and the intrinsic rewards are limitless for both partners and athletes. The partners also benefit by learning the responsibilities that come from helping their peers with mental retardation. Training and competition are supervised either by the club adviser or head coach. Club members act as assistant coaches, Unified Sports teammates, and boosters during school and Special Olympics competitions. Partners Clubs are sanctioned school clubs with all the benefits of any other school club. Partners Clubs usually have weekly or monthly meetings that follow school policies and procedures with elected officers. Partners Clubs need to have a faculty adviser and a student officer who through student leadership networks with school administration, athletic, and physical education departments.

## Special Olympics Unified Sports

Special Olympics Unified Sports combines approximately equal numbers of athletes with and without mental retardation of similar ability and age. Athletes must also have the requisite skills to play the sport to enhance meaningful participation and reduce the possibility of injury. Unified Sports is important because it expands sports opportunities for athletes seeking new challenges and dramatically increases inclusion in the community. A Unified Sports program provides an opportunity for people with mental retardation to be included on teams with people without mental retardation who are approximately the same level and age. The principle of ability and age grouping is fundamental to Special Olympics. It leads to meaningful inclusion on teams, a chance to be contributing teammates, and the potential to form friendships with people from whom they have traditionally been segregated. Unified Sports programs are springing up in communities worldwide through parks and recreation

Photo by Ken Regan/Camera 5

departments, civic organizations, private and public schools, colleges, group home agencies, state institutions, corporations, and business owners.

## Athletes For Outreach

Sports have helped many individuals with disabilities develop to their full potential, giving them skills and self confidence to take charge of their own lives and be productive, contributing citizens. Empowerment is not just participating, it is also giving back! Athletes for Outreach is a Special Olympics program that trains athletes to speak in public on behalf of the Special Olympics.

## Special Olympics Facts

Founded in 1968 by Eunice Kennedy Shriver, Special Olympics has come a long way in 25 years! No longer a once-a-year track and field meet held every spring; today, Special Olympics is organized in more than 100 countries to bring year-round quality sports training and competition in 23 different winter and summer sports to more than one million athletes.

Special Olympics competitions are patterned after the Olympic Games, meets, and tournaments in both summer and winter sports are held each year in communities worldwide. States hold Games annually. National programs hold Games annually or biennially. State and national Games culminate in international Games every two years, which alternate between winter and summer sports. By divisioning athletes and teams of athletes according to their sports ability, Special Olympics provides an appropriate sports opportunity for every athlete. Divisioning by ability also gives every athlete a reasonable chance to win. Athletes from all divisions may advance to state, national, and international Games.

Sports training is provided by volunteer coaches. Many have been through Special Olympics training schools, which are provided in the various sports for coaches, officials, and event directors. More than 500,000 volunteers support Special Olympics across the country. Many of the coaches are special education teachers, physical education teachers, recreation professionals, parents, or others who are involved on a daily basis with persons with mental retardation.

## Volunteers Are Vital

Most volunteers are like Ted March, a special education teacher in Roseburg, Oregon. One day, Ted noticed that a student, Larry Swanger, had an exceptionally strong hand grip. He convinced Larry to enter the school arm wrestling contest. Larry won the

the other children at school either hit her, ridiculed her, or ignored her.

Linda used Special Olympics sports training to draw Sary out of her shell. Linda first asked Sary to become a Special Olympics cheerleader. Then Sary became involved in athletics, ice skating, aquatics, and volleyball. Suddenly, Sary began to soar! She wears her skiing lift tickets on her jacket as a badge of honor. Sary has appeared in public service television announcements with the Philadelphia 76er's basketball team and with saxophonist Grover Washington, Jr. All these activities not only helped Sary change the way she felt about herself, but also began to change the way others at her school and in her community viewed her and others with mental retardation.

As Linda Carroll describes it, "These other kids would die to do what they saw Special Olympics athletes like Sary doing. Before it had been a derisive 'Look at them'. Now it is, 'Can we come, too?'"

Sary Sosa's reading ability climbed at least three grade levels in a year. Her self-esteem climbed at even a faster rate. Boys like her. Girls like her. As Linda Carroll puts it, "She's hot!"

Children with mental retardation often lack the prerequisite physical and social skills necessary for successful sports participation and are often isolated from peer group relationships and community and school activities. As a result, people with mental retardation often exhibit immature motor and social skills. Sports participation not only helps develop fine and gross motor skills, stamina, and strength—all of which are needed to work full-time in labor intensive jobs—but also teaches and reinforces social skills needed to get along in the workplace. Skills like cooperation, team spirit, self-discipline, perseverance, attentiveness, competitiveness, and working toward a goal are needed for competitive employment and for successful friendships. Sports help to develop friendships with teammates and open new avenues of communication between people with and without mental retardation.

## EARL SNOW— Swimming His Way To Independence

Earl Snow, a 36-year-old resident of Oklahoma, does not have pleasant memories of his childhood. Earl spent his early years in an institution and he remembers those days as frightening and frustrating. But he does have one positive memory from that time—it was there that he learned to swim.

Earl's first swimming instructor and coach was Terry Kerr, who today is executive director of Oklahoma Special Olympics. Terry remembers Earl as a "natural swimmer." In addition to whatever natural ability he had, he also possessed the drive to make himself work hard. His diligence in training was extraordinary—swimming daily until he was too exhausted to continue. The result of all this hard work and effort wasn't limited to his success in the water. It helped Earl build courage, inner strength, and the willingness to work hard at everything he did. Armed with those new-found qualities, Earl was able to leave the institution and move into a group home. Still he continued to swim and his skills continued to improve.

Earl joined Special Olympics and in no time was dominating local Special Olympics swim meets. Still not satisfied, he kept working. Swimming opened the door of the institution, allowing Earl to leave, and it opened other doors to him as well. His swimming prowess helped Earl become a certified lifeguard for the YMCA where he worked for several years. Today, Earl Snow lives on his own and holds a job to support himself, and he's still swimming. But now, in addition to swimming, he has learned to coach other swimmers.

## J.J. VAUGHN— The Determined Eagle

To achieve the rank of Eagle in the Boy Scouts is an outstanding accomplishment. It takes hard work, discipline and plain, old-fashioned determination. Those who earn it usually do so in their late teens. Ask if it's possible to earn the rank of Eagle at the age of 12, and

Photo by Ken Regan/Camera 5

contest and became a school celebrity, which left him hungry for more. He decided to try Special Olympics.

It was not easy. Larry, who is legally blind in addition to having mental retardation, spent most of his youth sitting and nodding his head back and forth, trying to stimulate himself visually. He had been in and out of foster homes and never had consistent training to enable him to develop eye focus and concentration skills. As a result, Larry was lethargic, unmotivated, and rarely put out any physical effort whatsoever.

Ted March started by simply having Larry walk around the track. As he progressed from walking to running, Ted had Larry run with his legs wide apart, to give him better balance and more control of his movements. After months of this broad-based running, Larry began to visually focus on the ground. His perception and body awareness progressed to where he was finally able to train on his own. Ted taught Larry to run on rural Oregon roads by following the yellow line on the shoulder.

One day, not long after Larry had begun training on his own, Ted was startled to see a figure running right down the middle of the highway. As he drew closer, he realized it was Larry doing as he was trained to do—faithfully following the yellow line; except this line was in the center of the road, not along the shoulder.

That doesn't happen anymore. Larry Swanger is an accomplished runner. So accomplished, in fact, that he has completed the Portland Marathon twice, and the Boston Marathon once, in a time of 4:02. Larry has also added basketball to his list of sports. Distance running and basketball have stimulated Larry's desire to achieve and has improved his self-confidence. Larry has worked full time for the past six years, coaches other Special Olympics athletes, and is an active speaker on behalf of Special Olympics. Through Special Olympics sports, Larry has effectively negotiated the many obstacles in his path and is now giving back, though coaching and public speaking, a little of what has been given to him over the years.

For more information on Special Olympics and its Inclusive Sports Programs contact:

**Director of Outreach**
**Special Olympics International**
**1350 New York Avenue, NW**
**Suite 500**
**Washington, DC 20005**
**(202) 628-3630** ♦

your local Scout Service office will tell you its possible, but certainly rare. Then ask if someone with mental retardation could earn Eagle Scout by the age of 12. Most people think such an accomplishment is close to impossible—but most people don't know J.J. Vaughn.

Vaughn is a 14-year-old Special Olympics athlete from Illinois, and he did earn an Eagle Scout at age 12 after what his mother describes as a year of intense concentration and extremely hard work. In addition to that accomplishment, his determined, aggressive approach has earned Vaughn honors elsewhere as well, including Special Olympics. He has won gold and silver medals in bowling, basketball, and volleyball at state, regional, district and local Special Olympics competitions. His mother Laura believes J.J's involvement with Special Olympics has played a key role in his scouting success. "Special Olympics has helped J.J. get over being shy, and training for Special Olympics events has helped him earn his physical fitness badge on the way to earning his Eagle Scout honors."

J.J.'s determination has helped in other ways, too. When he entered middle school, he was told his class did not participate in Special Olympics. J.J. simply could not accept that. He wanted to continue in the program that both he and his parents felt had been such a positive influence on his life.

After family discussions, the Vaughns contacted Dave Severin, south central Illinois Special Olympics area director. They set up a meeting for J.J., his family, and Dave to meet with J.J.'s teacher and principal of the school. The Result? J.J's determination and persistence led 15 of his classmates to sign up and participate in Special Olympics. Severin gives all the credit for the introduction of Special Olympics into the school to J.J. "Talk about 'Each one, Reach one.' J.J. got his school and his teacher on the Special Olympics bandwagon."

Eagle scout at the age of twelve: started a Special Olympics program in his school...J.J. Vaughn is living proof that determination can be translated into achievements.

## STEPHANIE MARGARET SUN OI ZANE

Stephanie Margaret Sun Oi Zane and her parents agree on a great many things. One of them is that she always wanted to be a "star." And what a star this delightful young woman has become! In the water or on the ice, on the court or in the lanes, Stephanie is an accomplished athlete. But this Hawaiian's star qualities go beyond her accomplishments in sports.

After graduation from Kaimuki High School in 1987, Stephanie began working at MacDonald's. Her diligence and hard work at whatever she was assigned led to an interview with a local reporter, and the budding star became the subject of a feature article on the front page of the East Oahu Press. She didn't stop there. Her own skills and her knowledge of systems and procedures led to her assignment as a crew trainer at McDonald's, helping to orient new employees and acquaint then with all phases of the restaurant's operation.

Stephanie has addressed the Hawaiian State Labor Department council about her employment at McDonald's to urge the adoption of programs that will encourage more businesses to hire people with mental retardation. She was nominated for the Winners at Work Award, was one of the three finalists for the Pilot Club's Disabled Professional Woman of the Year award, has spoken to business women's professional clubs and is engaged in many other outreach oriented activities.

But nowhere does Stephanie shine brighter than in her work as a Special Olympians Athlete for Outreach, a program in which Special Olympics athletes attract others with mental retardation to become part of Special Olympics. Stephanie, who has Down's syndrome, was Hawaii's first Athlete for Outreach and has helped bring many individuals into Special Olympics. Stephanie's mother, Jonna, admits, "I wailed to the doctor that I didn't know how to take care of a retarded child. He promptly informed me that Stepahnie's needs and, therefore, her nurture, were exactly the same as for any baby and I should proceed accordingly! In other words, advice in the baby books still applied. Over the years, we have learned to deeply appreciate the wisdom of that doctor's counsel."

Jonna gives much of the credit for Stepahnie's self-confidence and social skills to her involvement in Special Olympics. She learned to swim at age six and soon began swimming competitively at Special Olympics events. Her determination and her success are exemplified by some of her prized possessions, the gold, silver, and bronze medals that attest to her skill in the freestyle, backstroke, and breaststroke events. Later she added winter sports to her activities and won a silver medal for speed skating at the 1985 International Special Olympics Games in Utah. Next came basketball and with it valuable new skills and insight about being a team player. She also loves bowling and never misses a practice.

As important as Special Olympics has been to Stephanie, the credit for her accomplishments must be shared—with Stephanie herself. Her mother agrees, "While we arranged for special education programs, swimming, hula, and piano lessons, it was Stephanie who learned to read, write, swim, and dance. Although we encouraged a circle of friends at school and in the community, it was Stephanie who formed friendships and learned the give and take of social relationships. We helped plan Stephanie's vocational education, but she earned her position as a regular, paid crew member at McDonald's restaurant. We are proud of Stephanie and thankful to the many people and organizations like Special Olympics that have given her a chance to participate and excel in the everyday arena of work and play."

# PROJECT EMPOWER:

## *Self Determination for Young Adults with Disabilities*

**Jack Campbell**
**Director**

Project EMPOWER

## Introduction

Project EMPOWER has its roots in a citizen-based task force convened by the Prince George's County, Maryland, Commission for Persons with Disabilities to conduct a service needs assessment of students with physical disabilities transitioning from school to adult life. The research conducted by the task force confirmed the experience that there has been a paucity of services, activities, and training for young adults with physical disabilities who are preparing to leave the protection of the school system for college or employment and adult relationships. Task force members, including school officials, service providers, advocates, and parents, determined that the system has not been providing these young adults with the skills and preparation necessary to be successful in their adult lives. The system has failed (1) to provide adult role models; (2) to teach skills essential for personal success, e.g., self-advocacy skills, assertiveness, decision-making skills, and interpersonal relationship skills: (3) to teach disability rights and laws; and (4) to teach these students how to access all services and activities available to their nondisabled peers. In response to their conclusions about the system limitations, the task force developed and submitted a "Self-Determination Project" grant proposal to the Office of Special Education and Rehabilitative Services (OSERS). The focus of the proposed project was on skills development in students enrolled in four County schools with orthopedic units. A three-year grant was subsequently awarded to the Prince George's County Private Industry Council, Inc., to develop a comprehensive, integrated transition program. This program was designed to identify and teach self-determination skills which would assist young adults with physical disabilities to realize their potential, to strive for independence, and to work towards becoming productive and confident participants in community life. The grant award gave birth to "Project EMPOWER."

The purpose of this article is to describe a program that uses experiential education activities and role modeling by adults with disabilities to help students with disabilities negotiate the transition from young adult to adult life. This article will describe Project EMPOWER by (1) discussing the development of the model; (2) identifying and discussing the project components; (3) evaluating the successes and limitations of the project; and, (4) sharing the plans for the future.

## Project EMPOWER

### *Project Development*

The goals presented in the grant proposal became the foundation and framework for the development of Project EMPOWER:

- to provide a forum for transitioning youth with orthopedic disabilities and their families to express their self-determined education and training needs;
- to provide opportunities for transitioning youth with disabilities to have adult mentors with disabilities who can demonstrate how self-determination is accomplished in real life situations:
- to provide training for youth participants in decision making, advocacy, assertiveness, and self-empowerment skills necessary for self-determination: and,
- to provide training to school personnel, educators, vocational rehabilitation staff, parents, and other persons on the promotion of self-determination skills.

In addition to these goals, Project EMPOWER is predicated on a number of philosophical stances: (1) in order to create an effective self-determination project, the development process, itself, should model self-determination, "i.e., the individuals who would be affected by this project should participate in the decisions regarding its implementation"; (2) positive role models are necessary to teach and encourage the development of self-determination skills; (3) new skills are best learned through an experiential training model that provides opportunity for practice; and (4) empowerment happens when individuals are successful at advocating for their rights. This philosophical framework is evident in the project.

To ensure participation and voice by the individuals involved in this project, a Citizens Advisory Committee was established. Students, family members, mentors, educators, and service providers are represented on this committee. They meet on a regular basis to provide feedback and input to the project coordinator regarding the project. Positive role models have been provided both by the hiring of a project coordinator who could model self-determination and self-advocacy skills, and by the development of the mentor-student match component of the project. The training portion of Project EMPOWER is experiential and practical so that it allows the students the opportunity to learn and practice new skills both in the "laboratory" setting of the focus groups, and in the natural setting of the real world.


Photo by Project Empower

*Major Components of Project EMPOWER*

Project EMPOWER is a multi-faceted, multi-dimensional project that requires the facilitation of myriad tasks and activities simultaneously. Although it is a difficult process to coordinate logistical details, mentor-student relationships, and program development tasks, Project EMPOWER can boast the success of several of its components: (1) training and skills development; (2) self-advocacy activities; *and* (3) mentor-student relationships.

The training component has survived a number of permutations in the effort to create a "user-friendly" program. The curriculum has been developed and altered to respond to the needs of the students who participate each year. The focus of the training has been on the development of self-esteem, assertiveness, communication, problem-solving and decision-making skills. The primary participants of the project have been students from two high schools. Each group met twice a month for two hours of training with a professional trainer using adult learning methods. In each year, the students have used their skills to make a consensus decision regarding an end-of-the-year activity that would involve/include all participants. The first year, the students developed and produced a variety show. The second year, the students planned an EMPOWER picnic and a trip to an amusement park.

The self-advocacy component was developed in response to student needs for real experience dealing with their disabilities in a world where barriers exist that block their free access to desired services and activities. This component used the context of two key pieces of civil rights legislation as the framework for the activities: the Fair Housing Amendments Act and the Americans with Disabilities Act. Students discussed the laws and discussed the impact these laws could have on their lives. Two field trips were designed to teach the students how the laws can work, and to facilitate their identification of their rights and what they can do to assert those rights. The field trips focused on adaptable/accessible transportation and accessible housing.

In September, the program staff began making arrangements for "Transportation Day" by contacting the schools and requesting a field trip. The objectives for the outing were: (1) to develop and use an accessibility survey; (2) to increase student awareness of accessible transportation; and (3) to practice advocacy skills. Through contacts at the Washington Metropolitan Area Transit Authority (WMATA), students received applications so that they could apply for reduced fare

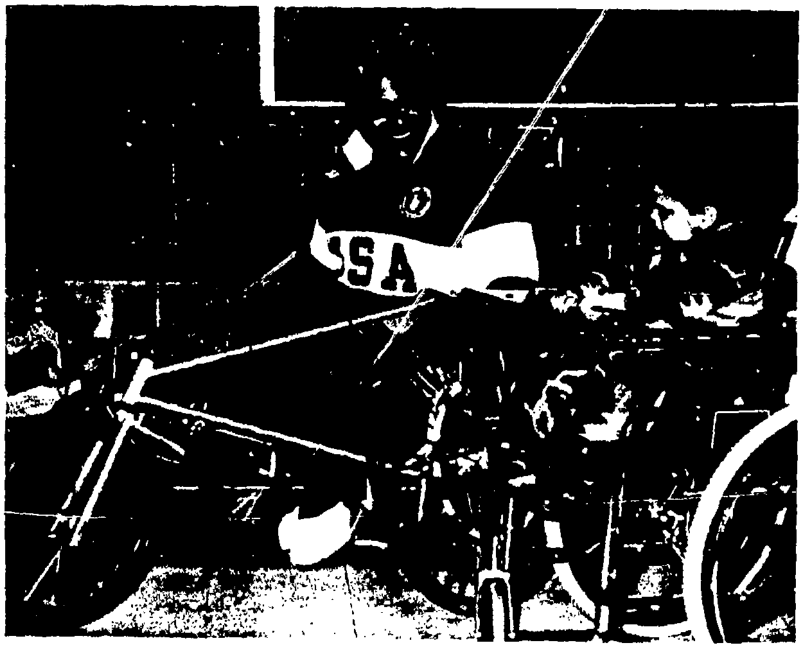

Photo by Project Empower

cards. Arrangements were also made to meet at the WMATA offices for a tour of the facility and to watch a demonstration of how lift equipped buses operate. After the tour and demonstrations, the students reconvened at a metro train station to embark on an experience with the mass transit system.

The students designed an accessibility survey to identify and evaluate barriers to their using the bus and subway system, stores, and food court in the mall. Follow-up discussions of the survey results, again using the context of the Americans with Disabilities Act, convinced the students to write a letter to one of the stores with suggestions for modifications and changes in the store design.

For "Fair Housing Month" twelve students visited a mid-rise apartment building to look at an accessible unit and to discuss housing adaptation. The students brainstormed ideas about accessible housing and then reviewed a resource guide on accessible features published by the Adaptive Environments Center which allowed them to identify several additional adaptations that could be made to improve the physical accessibility of the apartment. The building manager then took the group to a vacant "accessible unit" and entertained questions from the students regarding who was responsible for paying for changes, such as lowering kitchen cabinets, putting in ramps, and moving thermostats.

An experientially-based curriculum guide has been developed and will include procedures for implementation and suggested instructional content focused primarily on community-based organizations and integrated with activities for use by mentors, volunteer trainers, school based personnel, and families.

*Mentoring*

Many of the mentors recruited for Project EMPOWER have had disabilities since birth. Many also reported that, during their youth, they had no contact with adults who had physical disabilities, and consequently, they had no role models for success. The mentor program provides students with an optimistic perspective on the personal growth and the opportunities available to them.

Project EMPOWER mentors are people with real lives. Dick is a computer scientist, Bill is a programmer, and Nancy owns her own home and has two very lively children. Also volunteering are a civil rights lawyer, a House Select Education Subcommittee staffer, a community organizer for wheelchair sports, and an avid scuba diver. Attempts are made to match mentors with self-expressed student needs and interests.

Project EMPOWER can boast about the successes of its mentor component:

- One student received a $2,000 scholarship as the direct result of coaching from her mentor. She wrote a winning essay to receive Maryland's Disabled Teenager of the Year Award by the Maryland Governor's Committee for Employment of People with Disabilities.
- A student will receive a four-year scholarship to play wheelchair basketball as the result of his athletic talent and his mentor's involvement.
- A middle school student will be getting computer equipment to help with his homework thanks to mentor intervention.

Experience indicates mutualitity in these relationships. The adult mentors feel very positive about contributing to the program and about giving something back to the community through their friendship and sponsorship of a student. The students experience the encouragement and support of a successful adult who also has a disability.

Project EMPOWER staff have targeted 25 students to be paired with mentors for the 1992–93 school year.

*Findings*

Project EMPOWER was developed for students with physical disabilities who provide a different framework and different set of challenges for program development. Project EMPOWER is proud of a number of successes:

## Successes

- Obtaining funding to provide lift equipped transportation
- Obtaining funding to sponsor mentor activities
- Conducting forums away from the school environment
- Focusing on group development and team building
- Allowing students to devise and apply basic rules by which they can govern themselves
- Allowing students to choose three or four events or activities per year which are "just for fun"
- Giving priority to mentor matching of adults with disabilities to students needs
- Choosing trainers with disabilities gives a powerful message to the students
- Encouraging parents of EMPOWER students to organize informal support networks
- Providing consultation to school administrators regarding transition
- Disseminating information about Project EMPOWER activities

## Limitations

- Conducting forums in after school time frame (Would other time frames be more conducive to participation and learning?)
- Groups too large for personal discussions (Keep it small—6–8.)
- Vague objectives for activities (Are concensus objectives discussed ahead of time?)
- Transportation problems—(Are there several contingency plans?)
- Being overly cautious in mentor matching (Can matching system be kept flexible enough to allow for reassignments?)
- Having school systems the primary sponsor (Can self-determination prosper where students are referred to as "wheelchair bound," as having "birth defects," or as being "victims," or "Eddies" (special education students)?

### *Plans for the Future*

Subjective evaluation of the training component of Project EMPOWER identified two critical areas of skill development that demanded increased focus: social interaction skills and self-esteem. Bi-monthly training did not seem to be providing the intensity required to learn and practice new skills, nor to receive constructive feedback on individual progress. Achieving competence in social interaction skills requires practice and feedback. Students need to hear from others on how their behavior facilitates or hinders the development of friendship, but most environments do not provide a safe, non-threatening opportunity to do this personal growth and development work.

Project EMPOWER is developing a weekend residential intensive human interaction experience that will be piloted in 1992 or early 1993 with 6-8 students participating. The weekend will begin Friday evening and will conclude Sunday at lunch. The students will be working in groups with two facilitators. The focus of the weekend will be on communication skills, assertiveness, problem-solving skills, group behavior, collaboration, and team building. The students will have a "laboratory" experience in which they can look at and analyze their behavior and its impact on the other group members, and in which they can practice new behaviors. The focus will be on the "here and now," and on the relationships between and among the members of the group. Plans include providing a session on collaborative games and physical challenges conducted by a recreation specialist. All activities will be discussed in the group sessions. It is anticipated that the participants will have an intense experience in which they can get new information about their behavior and its impact on others, and can decide how (or if) they want to change their behavior in response to feedback. It is expected that the participants will leave this weekend feeling better about themselves and about their relationships with their peers, and will have a


Photo by Project Empower

Photo by Project Empower

better idea of what they can do to develop and retain friendships.

Follow-up sessions will be conducted monthly. The group will stay together, and will continue the group model for one three-hour session each month. Participants will continue to look at their behavior, and problem solve and role play difficult situations they experience in their lives outside of the group. These sessions will be facilitated by the same two trainers.

The planners/consultants believe this model will have a dramatic impact on the participants' skill levels and, subsequently, on their self-esteem. In order to assess this hypothesis, research will be conducted to compare this residential model with the current training model. Researchers/staff will conduct pre- and post-self-esteem assessment for both the new residential group and for participants in the bi-monthly training model. Efforts will be made to match the participants in the two groups, and to control for other factors that might affect self-esteem, e.g., school placement.

## Conclusion

Project EMPOWER was born out of a community-based task force. The model blended four basic components (1) a community-based citizen responsive advisory board; (2) students with physical disabilities matched with adults with physical disabilities; (3) an experiential, consumer-responsive, consumer-driven curriculum; (4) the education of parents, educators, and service providers in how to allow students room at home, in school, and in programs to become self determining by creating an environment where students were able to become more self determining.

By combining the efforts and resources of the community, students can be given the opportunity to gain control of their lives. They can learn to recognize discriminative situations and practices for what they are and to advocate for solutions. Through the model program in Prince George's County, Maryland, students are gaining a foothold in the planning of their own futures.

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# Empowerment Through Peer Counseling

Dale S. Brown

The President's Committee on Employment of People with Disabilities

As a volunteer in the self-help movement for people with disabilities, I have expended substantial time and effort counseling and assisting people who have disabilities. My experience, extending over twelve years, has led me to believe that peer counseling and building close relationships are key to personal empowerment. And that personal empowerment is the key to political empowerment.

What is personal empowerment? Personal empowerment is the ability to choose one's actions. A personally-empowered individual thinks and behaves as if he or she is capable, despite the negative messages about disability that are woven into our society. These negative messages not only affect the external environment of the individual who is disabled, but are often internalized. Frequently, the individual accepts as truth what he or she has experienced or has been told. This tendency of minority groups to accept negative stereotyping about themselves is often referred to as *internalized oppression.*

*External oppression* refers to both barriers and beliefs. An example of such barriers is an environment that disempowers or a system that strips people of their dignity. "Beliefs" refer to generally accepted tenets of society that imply that people with disabilities are somehow "less able" than people who are not disabled.

*Internalized oppression* occurs when an individual comes to accept these stereotypical beliefs as truths and acts upon them. For example, one negative belief held by society is that people with disabilities are not capable of working. As a consequence, people with disabilities might not try to find work. Or they may feel "grateful" to be given the chance to work. An individual who feels grateful might feel uncomfortable in asking for reasonable accommodations to enable him or her to perform at peak levels.

It is rare that an individual can throw off a lifetime of negative stereotyping in an instant without appropriate support from others. People who have received large doses of negative feedback from others or have experienced a traumatic event need to share their experiences and feelings before they are ready to tackle the next challenge. Unexpressed emotions tend to interfere with clear thinking and rational

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actions. An individual who becomes disabled from an accident often needs to grieve over his or her loss before becoming motivated to begin rehabilitation. Listening to an individual express those feelings is a powerful form of support that anyone can do. It is particularly important for people who have experienced the negative effects of society's attitudes towards disability.

## Peer Counseling Techniques

During the 1960s and 1970s, two trends converged: the development of self-help groups and the use of peer helpers in educational settings. During the 1980s, as funding levels dropped for human services programs, peer counseling was frequently used as a cost-effective alternative to traditional services. The disability movement picked up on these trends, and during the early 1980s, many community-based independent living centers developed peer counseling programs. Additionally, community-based disability support and advocacy groups widely disseminated peer counseling techniques.

My work in the field of learning disabilities was on the cutting edge of that process. Leaders in the self-help and advocacy movements found that they were overwhelmed by people who wished to talk to them about their problems. We found that until people were able to "tell their stories," they could not empower themselves to take the next step in self-improvement or community work. However, it became clear that they needed to help each other, rather than to rely solely on professional support. We set up peer support groups and workshops to teach people to listen to each other. Hundreds of support groups and numerous peer counseling relationships were formed during the 1980s and are continuing today. Here are some of the most important peer counseling techniques:

- Listen well. Let the individual tell you the entire story.

  When he or she stops, ask open-ended questions such as:

  *"Tell me more. What happened next? How did you feel? What did you want to say?"*

- Look at the person with respect and approval. Your voice and eyes should show interest and the wish to hear more. On the telephone, say "Yes," and "Go on," occasionally so that your conversational partner knows you are listening.
- Resist the temptation to interrupt with a story of your own. It is important to ignore your own feelings and concentrate on the person who is speaking. Your friendly listening creates the atmosphere that enables the individual to empower himself or herself.
- Encourage the expression of emotions. Until the individual is able to express anger and hurt, it is difficult for him or her to make a rational choice or decision.
- Ask questions that connect the present difficulties with similar problems in the past. For example, a college student has a problem with a professor. The professor may have given him or her a bad grade, have been unwilling to make a necessary accommodation, or simply hadn't had time to assist the student. The student feels powerless and unwilling to talk to the professor. Or he or she discusses the situation defiantly. The peer counselor can help by asking the student for information such as:

  *"Did this happen before? How did you feel?"*

  *"When was the first time you experienced this?"*

  Perhaps the student has brought past negative experiences with parents or teachers to the current situation. The peer counselor might ask, *"How is this situation different from the past situation?"* Sorting out today's experience from yesterday's experiences is helpful.

- State the truth and bring out the positive reality. For example, many people with learning disabilities feel they are stupid. It's important to tell the individual how smart he or she really is and encourage thinking of examples to prove it. The individual who feels "grateful to have a job" needs to understand his or her own worth. Perhaps the employer is the one who should feel "grateful" to have the individual with a disability on staff.

## Obtaining "Counseling" for Yourself

Most people find listening to others a deeply satisfying experience. A husband listened to his wife for ten minutes without interruption during a "listening skills" workshop exercise.

*"I never knew how eloquent she was,"* he told the participants. Many people with disabilities, able-bodied allies, and family members all agree that they learn more about their peers from five minutes of listening than they did in years of meetings with professionals.

However, listening can be hard work. Particularly if their problems remind you of your own, it can lead to early burnout.

It is important, therefore, to find equal time for yourself. Find someone with whom you can talk about your own difficulties. Express yourself. Think aloud. If they cannot listen well, find someone who can.

## Support Groups

An easy way to organize people for personal empowerment is to hold regular meetings of support groups. Support groups come in many formats: learning from experts, "twelve step" groups, discussions, and group therapy sessions. Each organization that encourages support groups has its own policies and counseling techniques. Many support groups are freestanding, that is, developed by a community member who wants to organize people who share similar problems.

A support group can be organized by anyone, a volunteer or a professional, a person with or without a disability. The format requires no agenda, no work, and limited planning time on the part of the leader. Keep the group small (ten or less) and follow these steps:

- Ask everyone to share some good news, preferably something that has nothing to do with the issue of disability that bought the group together.
- Divide the amount of time remaining in the session by the number of people in attendance. Subtract two minutes. Give each person that amount of time to answer an open-ended question such as:

  *"What is it like for you to teach children with disabilities in your classroom?"*

  *"What was it like growing up with a disability?"*

  *"What is the key issue facing you right now? How are you planning to tackle this issue?"*
- Each group should select a "chief listener" whose job it is to ask open ended questions and encourage expression of emotions. Toward the end of each individual's "turn," the chief listener should turn the speaker's attention away from his or her problems. This can be done through small talk or a discussion of daily activities.
- Most groups have some sort of closing in which each person talks briefly. Each group member might want to set a goal for next week or talk about something that he or she enjoyed about today's session.

These groups can become quite intense and, as trust develops, people share deeply of themselves. For this reason, everyone must agree to confidentiality.

Individual peer support that people can give to each other, formalized peer support where two people meet and share time, and support groups all have the same goal—enabling people to express their experiences and feelings. This gets rid of negative emotion and leaves room for positive action. Empowerment is more than a political term; it is the process of taking charge of one's life. This empowerment happens more easily if peers support each other through listening.

Often, a personally-empowered individual will realize that many of his or her problems are caused by societal forces. This realization enables that person to stop internalizing blame, to want to become active in the community, to challenge discrimination, or to help others. Then they begin the process away from personal empowerment to political empowerment. ♦

*This article does not necessarily reflect the official position of the President's Committee on Employment of People with Disabilities.*

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# Improving the Quality of Community Living to Empower People With Mental Retardation

**Charles Lakin, Ph.D., Director**

Research and Training Center on Improving Community Integration for Persons with Mental Retardation

In June 1989, more people with mental retardation (51.4 percent) were living in community residential settings (by convention places with 15 or fewer residents) than in larger institutions. The milestone of the community majority is an important accomplishment in this nation's quarter century commitment to deinstitutionalization. As shown in Figure 1, this commitment has brought state mental retardation institution populations from nearly 195,000 people in 1967 to 87,100 by June 1989. It reduced the number of people with mental retardation in state psychiatric units from 37,600 in 1960 to 1,500 in June 1989. But deinstitutionalization has had its "side effects," too. Notable among these were the transfer of tens of thousands of persons with mental retardation to nursing homes (over 37,000 in June 1989) and the development of large private institutions (45,500 residents with mental retardation in June 1989). Still as Figure 2 shows, there has been a major general shift toward community living opportunities for persons with mental retardation in recent years.

The Research and Training Center for Residential Services and Community Living (RTC) at the University of Minnesota with its collaborating programs at the Center for Human Policy at Syracuse University and the University Affiliated Program on Developmental Disabilities at the University of Illinois at Chicago was initially funded by the National Institute on Disability and Rehabilitation Research (NIDRR) in 1988. Its primary purpose has been to contribute to the expansion of the number and quality of opportunities for persons with mental retardation to live in natural communities. Six general areas of activity are viewed as essential aspects of this purpose:

(1) increasing the presence of persons with mental retardation in communities;

(2) promoting essential protections of basic health, safety, and recognition of rights and dignity;

(3) enhancing personal growth and development;

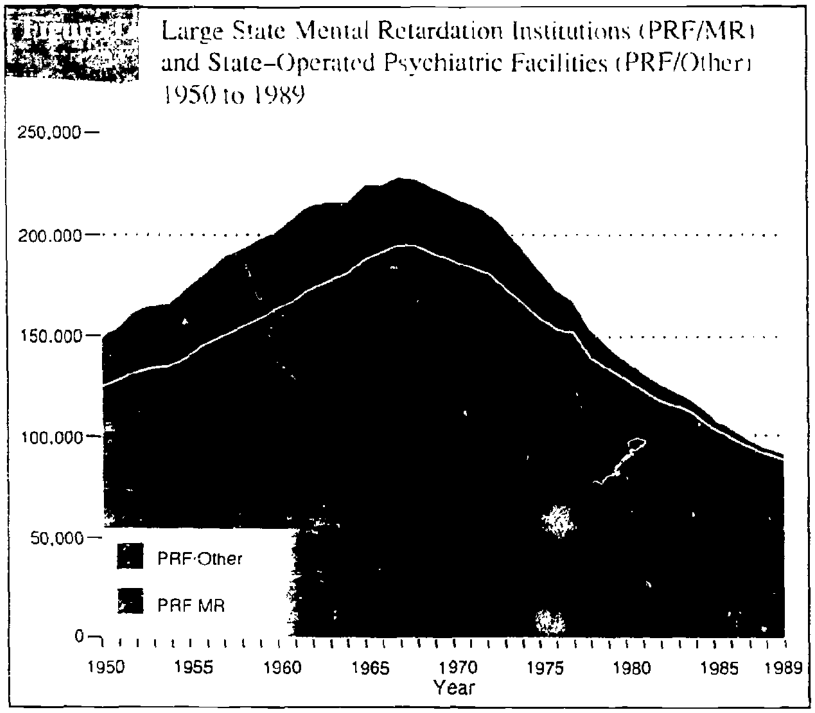
(4) fostering enjoyable social relationships;

(5) expanding opportunities for participation in roles valued by the community; and

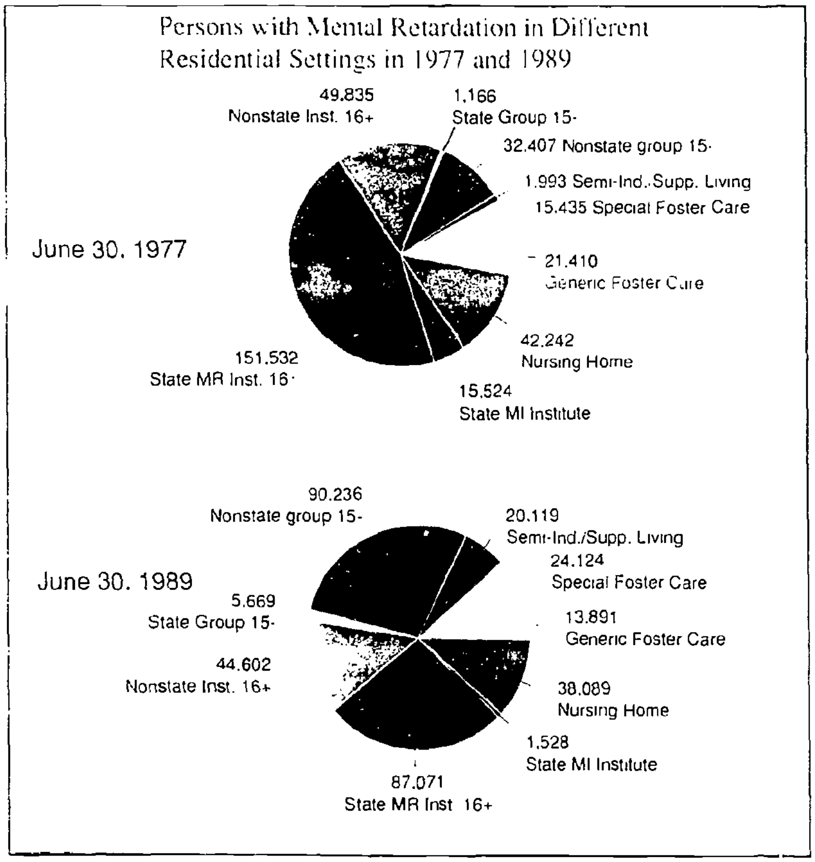
(6) increasing personal independence and self-representation.

## Community Presence

Concern for the quality of life of persons with mental retardation begins with assuring opportunities for all to experience the challenges and benefits of community living. People with all severities of mental impairment, including persons with profound mental retardation and serious medical problems, live in our communities. Their numbers are rapidly growing. On June 30, 1982, about 6,000 persons with profound mental retardation lived in community residential settings; by 1989 there were approximately three times that number. However, despite the dramatic increases in those individuals living in community settings, as of June 30, 1989, 170,000 people with mental retardation were still living in institutions. Systematic discrimination in access to community living opportunities continues against persons with the most severe impairments, despite evidence that they benefit as much



Large State Mental Retardation Institutions (PRF/MR) and State-Operated Psychiatric Facilities (PRF/Other) 1950 to 1989



Persons with Mental Retardation in Different Residential Settings in 1977 and 1989

from opportunities for community living and participation as less severely impaired individuals. The challenge remains to demonstrate that the resources of communities are essential to the well-being of all persons with mental retardation.

It is important for policy makers to be aware of the abundant evidence of the enhanced developmental outcomes associated with community living. Policy makers need to understand that the frequent parental opposition to deinstitutionalization turns into overwhelming support once parents see how their children benefit. Additionally, policy makers should understand the needs of family members in the difficult transition to community living and how focused programs can respond directly to those needs. They must understand state agencies' and community providers' strategies for financing integrated community living and employment, and be aware of the impact that government policies have on state and provider efforts. Policy makers have a critical role in assuring an adequately growing, stable, and well-prepared pool of personnel to meet the growing demand for community based services. Policy makers must learn to listen directly to people with mental retardation who are effectively speaking for themselves in matters pertaining to opportunities for improved community living and also develop an understanding of community life for people with mental retardation that goes beyond basic funding and legislation to include a responsibility to provide the comprehensive support for inclusion that can assure the full rights of citizenship.

The past two decades have brought some dramatic changes in the kinds of places where people with mental retardation live. During that period the major thrust in residential service policy has been to increase the amount of community housing. With community living being the typical experience today, more careful consideration is given to the extent to which the shift to community living has increased the power of people to control their social and economic lives.

"Supported community living" is a new way of thinking about community living in which the services are built around the unique abilities, circumstances, and needs of each individual. It begins with the premise that everyone wants a home that is more than a physical space to return to at the end of a day. The fundamentally important part of this concept is personalization; that the determination of what supports one receives because of a disability will not determine the individual's life circumstances, but will be used to shape and balance those circumstances.

The basic premises of supported community living are that:

- all persons need and deserve a home of their own;
- funding for housing should be separated from funding for services enabling individuals to choose where they live;
- services should support the preferences and lifestyles of individuals;
- the natural supports available to people through family, community, and friends should be sustained and fostered;
- people should have choice in services;
- methods of service delivery should vary with the individual; and
- service providers should find ways to bring services and supports into the homes of individuals.

Supported living as a practice is still affecting a relatively small fraction of persons with mental retardation. Nationally, fewer than 20,000 people with mental retardation are reported to receive either supported or semi-independent living services. Still the spread of the supported living concept can only foster the continuing decentralization and personalization of residential services.

## Basic Protections

People with mental retardation need opportunities to test and extend their abilities to live as independently as they can in their communities. But as they do so they should be assured of basic attention to their health, safety, and rights. Health research shows that persons with mental retardation in community facilities almost universally receive medical and dental services at least annually. In a recent survey in which 24 states responded to a request regarding the existence of written standards for state monitoring in 11 specific areas for Medicaid Home and Community Based Services recipients, 21 states indicated specific requirements in each of the areas of preventive medical care, medical care for acute conditions, medical care for chronic conditions, and emergency medical care.

Protections of basic safety and well-being are also a critical component of community services. Although the Life Safety Code and ICF-MR regulations help structure safety assurances in community settings, they are not in themselves sufficient protections. Basic assurances of safety remain a primary responsibility of public agencies overseeing community services. This responsibility involves assuring that formal program support and monitoring systems are adequate and that such protections must be supplemented by voluntary associations and mutual commitments among persons with mental retardation, their families, their friends and advocates.

Basic protections also mean assurances of basic rights and freedom from abuse, exploitation, and neglect. Such protections range from assurances that the rights recognized for people without disabilities are also recognized for persons with disabilities. For children this means assuring permanency planning, the systematic preference for and support of the natural family. The number of children and youth with mental retardation placed out-of-home was reduced from about 91,000 in 1977 to 48,500 ten years later. Still, significant challenges remain in providing needed supports to families and in assuring that permanency planning requirements for children receiving child welfare services are also extended to children with mental retardation whose services are funded by other programs.

## Growth and Development

People with mental retardation, like everyone else, need to learn new skills that enhance their competence and enrich their lives. Research has shown that the functional skills of living are better developed in those who live in community settings than in those who live in institutions. The most obvious explanation of this well-established outcome is that learning is not an internal process, but an interactive process involving both the individual and his or her environment. One learns the skills of society by living in society.

Increasingly, the focus of developmental instruction and supported participation for persons with mental retardation is being derived from the interests of the individual. The concept of "personal futures planning" often contains both general and specific processes for considering such outcomes within the context of an individual's desired housing, family involvement, social relationships, and activities. But expectations about the potential for persons with mental retardation to achieve levels of personal independence and participation in their communities remain considerably lower than for others. Well-demonstrated approaches to increasing independence and participation in daily community life are readily available in areas such as leisure and recreation, communication, art, and use of community resources. Effective integration and productive participation can be obtained with appropriate teaching and environmental accommodations.

Fully realizing the potential of persons with mental retardation in community settings is dependent on the quality and preparation of those persons providing personal support. The recruitment, training, and retention of direct care personnel presents a continuing challenge. The annual rate of staff turnover among the approximately 100,000 full time direct care personnel in community residential settings averages more than 50 percent. The highest educational attainment of the vast majority of individuals in these roles is a high school diploma or its equivalent, and few have had any specialized training other than that provided by the agencies for which they work. Clearly there is a substantial need for systematic approaches to training persons in such roles, but requirements for training and systems for delivering it are limited. Although demonstrably effective and promising practices exist in the training area, much improvement is needed if direct care personnel are to be able to contribute fully to enhancing the skills and community participation of individuals with mental retardation.

Photo courtesy of Charles Lakin

## Social Relationships

Social relationships are a key to quality of life for all people. Relationships with family members are usually among the most important. For persons with mental retardation, there are especially compelling reasons to promote sustained family involvement. Family involvement in the lives of persons living in the community is notably higher than for those living in institutions. Still many families are dissatisfied with their limited communication with community service providers.

Although people with mental retardation derive many of their social relationships from people with whom they live and work, most social relationships for people with mental retardation are with paid staff. When compared with the general population, community facility residents with mental retardation are much less socially integrated than the nondisabled population. However, research has begun to document effective methods of promoting and sustaining meaningful social relationships for individuals with mental retardation. These methods include various activities to promote the continued use of family social networks, churches, schools, and civic organizations to initiate mutual social involvements.

## Valued Social Participation

Being part of a society means contributing to it and participating in its resources. In a recent comparison of a random sample of 336 persons in small community residences and a random sample of 100 persons in the general population, community resource use was proportionately higher among people with mental retardation. Valued participation means more than drawing on the resources of a society, it also means contributing to those resources. In our society work is the most valued way for adults with mental retardation to contribute. Supported employment has been the most visible method of helping persons with mental retardation to contribute. Increasingly, however, questions are being raised about the extent to which supported employment programs are providing integrated and valued roles for participants.

Photo courtesy of Charles Lakin

## Self-Determination and Self-Representation

Increasingly, "empowerment" is recognized as an important goal for people with mental retardation. Empowerment subsumes a wide variety of skills and opportunities in the areas of independence, self-expression, choice-making, and self-representation. Skills in these areas and the opportunity to use them are fundamental to membership in society. At the most basic level, empowerment begins with the ability to communicate one's own preferences. Because of the growing numbers of persons in community settings with extremely limited abilities to communicate, the teaching of the most basic skills of understanding and expressing choice is a major challenge in community training programs. For many people with mental retardation, empowerment begins with learning how to initiate and exit interactions with other people. Improving the technology of teaching communication skills to nonverbal individuals with severe/profound mental impairments increases in importance as the number of people so impaired increases in community settings.

In expressing choices, augmentative and alternative communication is a key element in the empowerment of persons with mental retardation. In developing augmentative and alternative communication strategies and skills, the goal is to identify signs, symbols, or devices that assist the individual in self-expression. Clearly, for persons needing such assistance, the augmented ability to communicate is fundamental to individual empowerment.

It is critical that opportunities for self-representation by people with mental retardation be increased in program development and evaluation and in policy related areas. Conferences and working groups on self-determination and self-advocacy led by persons with disabilities have identified useful methods for enhancing effective self-representation and advocacy. These methods range from increasing self-advocacy skills to increasing the opportunities for self-advocacy through organizational development, and enhancing expectations that people with mental retardation be part of the process of making program and policy decisions that affect their lives. Finally, between instruction in the most fundamental aspects of making and communicating choice and participation in broad program and policy decisions, there is an ongoing need to view self-determination as an integral part of the skills and opportunities needed by persons with mental retardation to make the most of community living. Promoting opportunities for persons with mental retardation to develop to their full potential and to exercise their full rights of citizenship requires much greater attention to opportunities to make and act on choices in all aspects of daily life.

Progress is being made in providing opportunities for people with mental retardation to live with security in the community with opportunities to grow and develop, to establish mutual relationships, to participate in social roles that are valued, and to exercise control over their own lives. Realistically, however, the struggle for full citizenship for persons with mental retardation has just begun. Institutional placements are still common and within community living arrangements, elements of institutional living are still all too evident. Thousands of people nationwide await community living services that are currently not available. The advent of the "community majority" is shifting attention to the quality of community living. In the process it will be increasingly important to involve people with mental retardation, their families and friends in defining what quality in community living means to each individual.♦

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AN OSERS News In Print SPECIAL FEATURE

# Empowering Teachers To Help Students With Language Disorders In the Mainstream

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## Introduction

Because language dominates the classroom in the early grades, children who have language disorders and are in regular classes during grades 1-3 encounter significant difficulties. Here, says Cazden (1973), language "is both curriculum content and learning environment, both the object of knowledge and a medium through which other knowledge is acquired" (p. 135). Learning how to listen, speak, read, and write—the four cornerstones of language arts instruction—takes precedence in the early grades. Yet, in order to learn how to listen, speak, read, and write, children need to rely on these very processes. Since the same area in which the child's performance breaks down constitutes the essence of the curriculum, a situation develops wherein there is an "asynchrony of individual abilities and curriculum requirements" (Bashir, 1987).

The present study, funded by the U.S. Department of Education, Office of Special Education Programs, was designed to help mainstream teachers in Grades 1-3 facilitate language learning in students who have language disorders. The overall approach to language arts learning and teaching fostered by the project is a constructivist one, in which teachers facilitate the meaning-making process over time in an environment that depends heavily on collaboration among peers (Englert and Palincsar, 1991; Bos, 1991). This type of approach closely resembles the basic tenets of what the literature calls the whole language approach (Goodman, 1989; Smith, 1988).

## Study Design and Method

The project, spanning three years (October 1988—September 1991), involved intensive training and research with ten teachers from three school districts in Massachusetts. Over the three years, while the teachers were involved in the Education Development Center's (EDC) comprehensive intervention, project staff carried out a naturalistic research project to examine factors affecting teacher change. EDC wanted to understand what factors promote change in teachers' knowledge, beliefs, and practice.

The design of the intervention was guided by four principles of constructivist learning. EDC guided each teacher to identify a need related to an area within language arts or to a particular child that would **anchor** the change process (Samuels and Pearson, 1988). The intervention was designed to champion and nourish collaboration among teachers and between trainers and teachers. In this community of learners, the construction of knowledge was a **socially-mediated** process (Garmstrong, 1987; Joyce and Showers, 1982). The intervention was designed to be **recursive**, giving each teacher a chance to engage in multiple opportunities to gain new knowledge, shift beliefs, and change practices in as flexible a way as possible (Showers, Joyce, and Bennett, 1987; Long, 1983). Each year, we scheduled a series of workshops and provided intensive, ongoing technical assistance. Using a variety of training strategies, teachers had opportunities to return to recurring themes and issues about whole language instruction (Lester and Onore, 1990). The trainers **facilitated** the change process by modeling practices, demonstrating techniques and strategies, and providing resources. Teachers and researchers worked together to plan instruction, implement new approaches, and reflect on practice (Sparks, 1983).

Three elementary schools in Eastern Massachusetts, with fairly similar characteristics, participated in the study. EDC followed the same set of ten teachers longitudinally over a three-year period. EDC collected teacher data through conducting individual interviews each year, observing in classrooms, administering the Statements of Concern (Hall, 1987), gathering workshop evaluations, and gathering information during informal debriefings. Data analysis was a multi-step recursive process that included analysis of field notes, analysis of workshop evaluations, analysis of Statements of Concern, individual assessments of each teacher to develop a training plan, case studies of each teacher's change over time, timelines of participation in the intervention's main events, a Practice Profile, and a matrix analysis that allowed for comparison across teachers.

## Findings

The project's results are described in three ways: (1) descriptions of overall changes in practice; (2) cases of individual teacher change; and (3) factors promoting or hindering teacher change.

We have documented the ways in which the ten teachers changed their practice in three areas: the organization and climate of the classroom (physical arrangement, accessibility of materials, displays, and management structures); reading instruction (materials, instructional strategies, and assessment); and writing instruction (process writing, journals, and acceptance by teachers). Some of the most consistent changes were in classroom organization and climate. For example, many teachers changed the desks from rows to clusters, installed learning centers, reading corners, rug areas, and message centers, and allowed students more freedom of movement. A large number of teachers made changes in the areas of reading, changing over to trade books and abandoning isolated skills teaching. In terms of writing, by Year 3, many teachers gave students autonomy to write about their own topics and facilitated the process by brainstorming, conferencing, publishing, and allowing sufficient time for drafting. All the teachers had students write in journals, some on a more regular basis than others.

For each teacher, we wrote a case study depicting the way that teacher changed over the three-year period. Of the ten teachers, four teachers made extensive change, three made moderate change, and three made minimal change. As an example of a teacher who made extensive changes, one third-grade teacher went from adhering strictly to a basal reader format with an emphasis on skills and assessing students on unit tests, to running a literature-based reading program using trade books only. As an example of a teacher who made moderate change, a second-grade teacher went from classroom writing as a lockstep process, all children writing at the same time on the same topic, with the same story starter, to process writing based on thematic units. Twice a week students were given autonomy to write on their own, taking as much time as they needed to do it, allowed to use invented spelling, conferencing with peers and teacher, editing and elaborating as they went along, and publishing their own books. As an example of a teacher who made minimal change, a second grade teacher went from a strict basal reader format, emphasizing skills, to a more relaxed format, still using basal readers, but also using trade books and abandoning workbooks for independent learning.

We identified three sets of factors that had an impact on the change process: (1) teacher, (2) intervention, and (3) context. Teacher factors include a teacher's ability and desire to reflect upon and analyze experience,

[illegible]

***Year 1***

Entering Marilyn's third grade classroom, one was struck by the quiet. Students sat in their seats, in rows, filling in worksheets. Marilyn explained she preferred this arrangement "to reduce social interaction during lesson time." She expected her students to be well-behaved and on task. The room was decorated with some teacher-made and commercial materials, and a few student work papers that demonstrated perfect or corrected work. For much of the day, Marilyn sat at the reading table working with reading groups where she used the basal reader exclusively. Using the Ginn Basal Reading Program (the Reader, Workbook, and Skillpack) with her three homogeneous reading groups. All of the students with language disorders were in the lowest group. She assigned every story and every page of the two workbooks to each group. In a typical 20-minute reading lesson she spent about ten minutes going over the story, adhering strictly to the script in the teacher's edition. She looked for student responses to the scripted comprehension questions that exactly matched the teacher's manual. The remainder of the reading group time was spent correcting workbook pages. One by one, students were given a chance to read a sentence from the workbook and give the answer. She never asked for clarification, elaboration, or what led to the student's thinking. She said that the reason she followed the teacher's manual so slavishly was because she believed that the "experts knew what they were doing."

There was very little writing in Marilyn's class. When she did have a writing lesson, she used story starters. Students wrote a first draft, then had their papers corrected by Marilyn. She highly valued those papers that had a beginning, middle, and an end. She showed the class examples of what she labeled "acceptable" papers as a way of modeling instruction. She told us she didn't "really like to teach writing," that it was a difficult subject and that she "often could not figure out what to write about."

***Change Over Time***

We instituted three cycles of planning, co-teaching and debriefing in the spring of the second year. Marilyn was skeptical, worrying about "doing it (writing conferences) wrong" and somehow "ruining the children." She accepted help from the trainers. For example, watching the trainer run a prewriting brainstorming session, followed by writing conferences, she felt she could do it too. She tried the process on her own, using a problem-solving unit; however, she did not follow through and left the topic dangling for weeks before her class picked it up again. By then the initial enthusiasm had worn off. Nevertheless, Marilyn asked for more help with writing. By May of Year 2, she had moved the desks around to form clusters, but the walls were still bare and there were few resource materials (library books, trade books) available for students. Reading remained wedded to the basal reader and the worksheets, but writing had taken on a different character.

***Year 3***

By Year 3, Marilyn had made some dramatic shifts. She had abandoned the basal reader in favor of literature, and writing (using a process writing approach) had become an integral part of the curriculum. The change seemed to have occurred after the summer training which, she said, had stimulated her thinking. The basal reader and its concomitant three reading groups disappeared and all students, regardless of reading level, were reading from the hundreds of trade books bought mostly with her own money. As someone who worked part time in a bookstore, she carefully selected books that represented classics and good children's literature.

The desks were arranged in clusters of four or five to "promote collaboration," according to Marilyn. Bulletin boards began to include more of the children's original work. For example, a class story about the moon was displayed on the wall with edits in the form of crossed-out words and insertions with arrows. There was a listening center in one corner of the room, collaborate, and take risks. The intervention factors include how closely the intervention was able to help teachers be anchored, carry out a recursive process, be socially mediated, and facilitate the change process. The contextual factors focus on the teacher (her past experience and knowledge), the school's policies and programs (access to resources, administrator support, and the student body), and the intervention (participants, intensity, and duration).

We found that complex change in knowledge, beliefs, and practice is not a result of particular factors, but rather results from a dynamic interaction among factors. The teacher's abilities and desires interact with the elements of the intervention. Contextual influences interact with the scope of the intervention. EDC identified four critical factors that derive their power from the interaction of the separate factors listed above. These include dissonance (dissatisfaction with some aspect of teaching); chemistry (positive relationship between trainer and teacher that grows out of mutual respect and a desire to construct change together); individualization (tailoring of workshops and technical assistance to meet teachers' individual needs); and coalescing (the point at which knowledge and beliefs are consolidated and give rise to a unified set of new practices).

EDC found that the presence or absence of the critical factors contributed to extensive, moderate, and minimal change in teachers. All four critical factors need to be present in order for extensive change to take place. The change process is anchored because the teacher feels dissonance in some area of teaching/learning. The intervention, in response to the teacher's felt need is individualized in the ways described above. There is a positive chemistry between the teacher and trainer. At some point, momentum builds and is sustained because of the coalescing of new knowledge, beliefs, and practice. The critical factors that contribute to moderate change in teachers are dissonance, individualization, and chemistry. What is missing is the coalescing. Minimal change is characterized more by the absence of critical factors than by their presence. The only factor that is present is individualization; however, individualization is severely limited because the teacher has not clearly identified an idea of need. The need is really identified by the trainer, with some or often little ownership by the participating teacher.

## Recommendations

Based on the project's findings, we offer the following eight recommendations to those regular and special education administrators and staff developers involved in training teachers to use a whole language approach in their classrooms with students who have language disorders.

1. ***Create a Context for Change***. Administrator buy-in and support is extremely critical. Teachers need to be consulted about areas in which they think change is needed. Change that is directed only by administrators is not usually owned by teachers.

2. ***Be Selective about Which Teachers Participate***. Teachers must want to participate and volunteer for a teacher development project. They need to have a desire to change, a willingness to work closely with trainers and colleagues, and a willingness to take risks in thinking about new knowledge, changing beliefs, and trying new practices.

3. ***Train the Trainers in Constructivist Principles***. Translating constructivist principles into practice involves training the trainers. It is advantageous to a project to spend time training staff by explicitly discussing the role of the facilitator, role playing how trainers would act in certain situations, and simulating the teacher/trainer experience. It is also important to build in,

from the very beginning, support system for trainers.

4. *Choose Trainers Carefully.* It is more advantageous to have internal change agents than outside change agents. Outsiders have no real influence or power, although they can be "neutral," nonevaluative, and objective. A trainer or facilitator should be familiar and comfortable with constructivist principles, have an understanding of language development, language problems, and whole language approaches. He should also have excellent interpersonal skills, power to influence change, and have a flexible schedule.

5. *Support Fundamental Change Intensively Over Time.* Implementing a constructivist approach to teacher development can be labor- and time-intensive. Those who design a program to meet this goal must carefully consider how they will allocate resources over time. Time and support are needed for teachers to become aware of or to internalize various principles, to try out a variety of new techniques and strategies aimed at achieving those principles, and then "coalesce."

6. ***Adhere to the Constructivist Principles during Implementation.*** Both the participating teachers, and the trainers in the project, were products of the knowledge transmission, factory-based model of schooling. This type of teaching and learning has been firmly ingrained in all of us who fall within a particular age range. There were times that trainers offered too much advice, assistance, or direction, not letting the problem solving or thinking emerge from teachers. At the same time there was a tug in the direction from teachers to fall back on a knowledge transmission mode. Thus, it is important to build in training and ongoing support for the trainers.

7. ***Find Creative Ways to Provide Ongoing Assistance that Is Not Labor Intensive.*** The present project had intended to build a peer coaching program into the intervention, but was not able to do so. In designing an intervention, it would be useful to think about incorporating this from the outset to reduce the labor intensity of trainers.

8. ***Build in Ways to Monitor and Fix Up the Ongoing Intervention.*** It is important to build in some kind of monitoring system to know if the four critical factors that promote or hinder change—dissonance, chemistry, individualization, and coalescing factors—are present, and to try to strengthen the program if they are not.

## Conclusion

This project provided an outstanding opportunity to understand teacher change while teachers are engaged in an intervention based on constructivist principles. As the project ended, many interesting questions emerged that would guide our future work. A starting point would be to design an intervention that followed all the above recommendations. Also, in the next round of work, we would want to focus on student outcomes. In this project, we had a growing sense that the teachers' practices were having a positive effect on students. For example, students were beginning to write, to read with meaning, and to share their ideas with others. Further work needs to consistently document these changes to provide the fuel for bringing constructivist teaching and learning into the classroom. ♦

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equipped with headphones and tapes of children's books. The reading table was gone and a rug had taken its place. All students, including those with language disorders, were engaged in a variety of tasks: some read books alone or in pairs; some talked to one another; and some wrote stories. Students were encouraged to make their own reading selections. Time was set aside daily for silent reading. Many of the book-sharing activities took place on the rug, with Marilyn sitting cross-legged with students (who read at different levels) surrounding her. During these informal times, Marilyn engaged students in discussions, elaborated on their responses, and pushed them to think about what they had read. Her comprehension questions were conversational, open-ended, and invited discussion. Skills practice was integrated during reading time. More time for writing was gradually becoming a part of the curriculum; however, Marilyn's energy for change was focused mostly on reading.

*Continued from page 2*

awards for research and service delivery for minority individuals with disabilities. And we have increased support for programs that train and recruit special education and rehabilitation professionals. Improving monitoring activities and accountability of programs receiving federal funds has also been a priority of my administration. I am committed to ensuring that all individuals with disabilities receive high quality services and programs.

With the implementation of the ADA, opportunities to achieve independence in employment and community participation have taken a giant leap forward. But empowerment must still occur within the individual; it cannot be given to an individual by the education or rehabilitation system or legislated by government. We must create a climate in which individual empowerment can occur through the utilization of technology, research, innovation, and flexible delivery systems to assure that people with disabilities are prepared to take advantage of their new opportunities and to exercise their new options. When competitive employment in a career field of choice is achieved and when community participation leads to full citizenship with all its rights and responsibilities, then an individual may be truly empowered. We work toward this goal every day and we in OSERS are your partners in this effort.♦

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